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OLDER PEOPLE AND HOSPITAL DISCHARGE

**How service users', carers' and
professionals' experiences can
inform social work practice**

SUSAN MARGARET FOWLER

PhD

2009

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**How service users', carers' and
professionals' experiences can
inform social work practice**

SUSAN MARGARET FOWLER

A thesis submitted in partial fulfilment
of the requirements of the University
of Northumbria at Newcastle for the
degree of Doctor of Philosophy

Research undertaken in the School of
Health, Community and Education
Studies

August 2009

Thesis Abstract

Older people and hospital discharge: how service users', carers' and professional experiences can inform social work practice.

In an era of change in social work practice and policy, this small-scale qualitative study was conducted between 2003-06 with the aims of learning firstly about the experiences of older people leaving an acute hospital in Northern England; secondly, about social work input including multidisciplinary professional relationships regarding discharge and thirdly to look at the effects of 2003 delayed discharge legislation (reimbursement) upon key stakeholders' experiences. Although, as discussed in the literature review, there has been a great deal of attention in the past to delayed discharges and to care management performance, there has been little published research on social work or care management in the hospital environment post-reimbursement. Policy and practice background is also explored in the thesis, which traces the development of concern regarding delayed discharge; trends within care management, and the wider agendas in social care policy for older people and their informal carers.

The guiding methodological approach to the research is phenomenological and an open-ended research study was conducted seeking to discover the lived experiences of older people who were leaving hospital. Twenty-nine semi-structured interviews were held with service users and carers. Five focused discussion groups were facilitated with health and social work professionals involved in the discharge of older people. The data from both sources was analysed thematically and presented in chapters on loss and transition, decision-making and relationships. In addition four illustrative case examples were constructed to aid understanding of the complete stories of the discharge episode for older people and their families.

Findings from service users' interview data included: a lack of understanding and in some cases lack of recall of social work input and experience of a rushed discharge. There were mixed views on information provision and user involvement in decision-making. Users welcomed approachability of social workers, as did their carers in addition to: availability, continuity, follow up and support to find a suitable care home for the older patient if necessary. In focus groups professionals discussed the changes to their work as a result of: faster patient turnover, increased administrative duties and of the effects of delayed discharge legislation. There were

reports of interprofessional tensions around overlapping roles, communication and differing perspectives of the discharge process for service users.

Implications of the study findings for social work practice, policy and methodology are explored later in the thesis. Drawing upon the data analysed there is discussion of the concept of hidden social work, the key messages from users and carers interviews and building on Postle's model of tensions in social work practice (Postle, 2002), a new model for hospital social work is presented. The thesis considers how social workers can reconcile those tensions within care management in a contemporary hospital setting. The conclusion reflects upon the scope of the research study and argues that in meeting the project aims an original contribution to practitioner knowledge has been made. The final chapter also sets the study findings in the context of past-published work and gives recommendations for future research and hospital social work practice.

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Acknowledgements

This research study was conducted with finance from a University of Northumbria studentship awarded by the School of Health, Community and Education Studies.

With grateful thanks for all their patient guidance, inspiration and just for staying with me - to my supervisors at the University of Northumbria:

Professor David Stanley

Professor Jan Reed

Also special appreciation to **Danny Golding** for his never failing practical and emotional help and encouragement, without which this thesis would not have been written, finished or produced in it's final form.

My thanks to the following for their continued help and support throughout the study:

Dr Russell Murray, Sue Hennessy, Katy Barton, Alan Clarke, Sue Capel, Jo Armistead, Lorna Kennedy and in the study locality: Joanne Holmes, Pauline Johnson and her team and **all the service users, family members and the professionals who gave their time so willingly.**

This thesis is dedicated to my son Max and my parents Margaret and Colin Fowler and is in memory of my Dad, Colin, who died in hospital in April 2007.

Author's Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

Name: Susan Margaret Fowler

Signature:

Date:

1 Introduction to the thesis

1.1 Introduction

This chapter will introduce the thesis, giving an overview summarising content and the aims of and rationale for the research study upon which it is based. Qualitative research was undertaken with service users, carers and staff on their experiences of social work practice and acute hospital discharge in one location in Northern England during 2004-6. The chapter will also outline the study context of theoretical, social policy and professional influences upon social work, further examined in Chapter 2. The importance of the personal experience of service users and social policy to social work and my study, can be summarised as follows:

‘The central challenge for social workers is never to lose sight of both the private troubles experienced by older people and the public issues that shape those experiences, as a consequence of the political, policy and organisational responses to them.’ (Tanner and Harris, 2008: 211)

The hospital discharge process was considered to be a useful point to focus upon social work practice, and service users’ views of this as it is at the ‘sharp end’ of the health/social care interface, in the operation of multi-disciplinary activity from assessment of older patients’ needs through to discharge arrangements in consultation with relatives, primary care, the independent sector and others.

My background is in social work practice and although I have chosen to look at it more closely by generating data relating to the social work role in hospital discharge, the processes and ‘who did what’ were not as important to me as how services users were treated, and the outcomes for them. Therefore in this thesis I describe and discuss service users’ and carers’ experiences of the discharge process. In doing so I was able to learn from them to create knowledge, which may cast some light upon the effects of social policy and assist in improving social work practice. I must also in writing this thesis, honour obligations to the participants and the contributions that they made.

This chapter is the first of five giving background information to the study, before presenting, analysing and discussing the data generated in the research project. The subjects of the other four chapters are detailed in the overview of thesis chapters in 1.6 below.

1.1.1 Overview of thesis

Chapter 2 in the first part of the thesis looks at social policy regarding hospital discharge and wider developments in social care and social work with older people. The latter has largely become the practice of care management (Tanner and Harris, 2008), as it was in the hospital where the study was conducted. This chapter also examines what led to and followed the enactment of legislation on delayed hospital discharges in 2003. A review of the literature on these topics in Chapter 3 focuses on themes around the effects of delayed discharge legislation, older people's involvement in the discharge process and the contribution of hospital social work to that process. However at the time of planning the research project in 2003, little published work had been found on social work and the hospital discharge of older people. My study therefore seeks to fill that gap, building upon earlier research studies. The discharge process was also viewed as a useful case example context in which to explore social work practice with service users, their carers and inter-professional relationships.

The overarching methodological approach was phenomenological, aiming to seek participants 'lived experience', and is described and discussed in Chapter 4. In order to generate qualitative data for the study, frequent visits were made to an acute hospital social work team during 2004-6. 30 semi-structured interviews with older service users and their carers following their hospital discharge were facilitated, in addition to five focus groups with professionals from relevant disciplines. Research validity and a number of ethical considerations are also addressed at the end of Chapter 4.

The locality where the study participants lived and background information on the social services department and the study hospital are the subject of the first part of Chapter 5. The data generation, sampling strategy, recruitment of participants from that locality and progress of the project, is then described. Interview and group sessions with study participants were taped, transcribed and analysed thematically.

An illustrative case example is presented in Chapter 6 giving a fuller description of the whole story of one patient to shed further light on data presentation.

Categories that emerged from service users' and carers' interview data were grouped under headings in Chapters 7-9, around themes of loss and transition, decision-making, and relationships. Among cross cutting themes found in data from

all participants' were: increased patient throughput, multiple moves, a rushed discharge process, lack of choice of post discharge location for some service users and a shortage of adequate information and resources. Additionally, the main issues from staff group sessions included changes of roles and tensions in inter-professional working.

The penultimate chapter (10) looks at the implications of the study findings with a discussion of a potentially diminishing contribution of social work to hospital care management with older people and the consequences for practice. The majority of older service users in the study appeared to receive variants of 'discharge planning'. The research has raised some interesting issues, which may feed into the current national debate about the nature of social work. For example, although social work has the potential to meet some of the pressing needs of older patients (Beresford, Adshead and Croft, 2006a; McLeod and Bywaters, 2000) it may be only able to do so for a few in the acute sector and then may do so 'invisibly'. Furthermore the thesis considers the extent to which hospital social work is constrained by reimbursement, managerialism and the operation of the NHS. As a contribution to knowledge, in a re-working of Postle's model (Postle, 2002), a picture of social work attempting to reconcile and negotiate tensions from within and without the profession is created.

The thesis concludes in Chapter 11 with reflections upon lessons learned from achieving the aims of the research project, areas for future research and its unique contribution to knowledge, with some final messages for the practice of hospital social work with older people.

1.2 Rationale for conducting study

To further clarify the approach to the research topic, I have been a social worker with older people in various locations and guises since 1989, with a change of job title to 'social care manager' in 2001. In these roles, amongst other duties I had been responsible for assessment of older patients' needs and for arranging post discharge services. During that period of practice, I witnessed the growth of optimism beset with major challenges. For example, with the National Health Service and Community Care Act (NHSCC) 1990 discrete social services for adults were reborn, together with official recognition of the need for user involvement (Great Britain, *National Health Service and Community Care Act* 1990). Such developments were accompanied by increasing rationalisation of provision for older

people with 'care managers,' no longer necessarily social workers by occupation, at the frontline (Means, Richards & Smith, 2003). Hence when Labour came to power in 1997 there were expectations among colleagues of improvements both in service levels for users and job satisfaction for social workers. From a professional perspective, it is arguable that major improvements in social care did not take place, with the imposition of a culture of targeting of services and performance management, as in many fields of public service (Tanner and Harris, 2008).

In 2003 the Community Care (Delayed Discharges) Act was passed, to address the situation of older people who were waiting long periods on hospital wards for care services. The legislation gives acute trusts power to fine councils for such older patients who are pronounced fit to leave hospital also referred to as 'reimbursement' (Great Britain, *Community Care (Delayed Discharges etc) Act 2003*) as detailed in 2.3.3. However, whilst there was simultaneously a much-needed increase in rehabilitative facilities for older people post discharge, proliferation of independent sector provision had resulted in an overall decline in care home places for some years with closures of many, usually smaller, homes (Commission for Social Care Inspection [CSCI], 2009a; Laing & Buisson, 2005). It was the combination of those closures – potentially impacting upon choice for older people leaving hospital - together with increased pressure for quicker discharges from 'reimbursement,' along with a desire to search for and present the voice of service users that formed the initial impetus for undertaking the research.

From a wider policy angle, plans have been afoot to extend the 'reimbursement' model to mental health, rehabilitation and other groups, so delayed discharge and the outcomes of policies to address it have remained topical and contested (Askham, 2008; Henwood, 2006; Lewis and Glasby, 2006). Government statistics have shown reductions since 2003 in the length of time older people wait in hospital to be discharged (see 2.3.4). There have also been reviews of positive multidisciplinary relationships to deal with post reimbursement working arrangements, partly due to the efforts of the Change Agent Teams (CAT) (Baumann et al, 2008; Swinkels and Mitchell, 2008; CAT, 2004; CSCI, 2004a; Hudson, 2004). The picture conveyed locally in 2003, in the hospital where I undertook fieldwork appeared to be different from the situation outlined in the last sentence. I needed to find out more and to sound out the opinions of service users and professionals. I therefore planned and undertook focus group sessions with all

staff groups involved in hospital discharge processes, in addition to individual interviews with older service users and carers.

The motivating factors for conducting the project were therefore threefold:

- A professional interest in the service users experience of social work and leaving hospital
- Concern for the impact of government policies, and specifically Delayed Discharge legislation - upon staff and patients
- Consideration of how social work can function in the current hospital and local authority environments

Policy developments and their implications for older people leaving hospital and for social work are explored more fully in Chapters 2 and 3 as outlined in 1.6 below.

1.3. Research aims

The project aims were as follows:

- **To explore how older people leaving hospital and their carers experienced the discharge process, focusing particularly on social work activity:**
 - How did older people experience coming into and leaving hospital, and the outcome of those events? What were the common themes identified from their reported experiences?
 - How involved did older people feel in decisions regarding their discharge and how much choice was available to them?
 - How did users and carers describe social work input? What were their opinions of this interaction?
 - How far were their psycho/social needs met?
 - How did the perspectives of these two groups differ?
- **To examine how social work operates within the care management model in hospital in the context of the discharge of older patients:**
 - How do social workers describe their role within this context? What common themes can be identified?
 - How can care management services to older patients and their families be improved?
 - What are the perspectives of other professionals upon the discharge process for older people and social work/care provision?

- How do social workers relate to other professions in this multidisciplinary setting, with regard to the discharge of older patients?
- **To investigate the effects of the Delayed Discharges legislation upon service users, carers, the professionals and their work, in the study hospital between 2004-6**
 - How has the legislation impacted upon the discharge experience for older people, particularly upon issues such as choice and user involvement?

In order to fully explore the topic, to look at the lived experiences of service users, at their pace and in recognition of the vulnerability of those in hospital or who had recently left, a qualitative, open ended type of enquiry which aimed to gain 'rich data' impressed as being the best option. I was neither testing hypotheses nor seeking an end product that could be generalized to the whole country or to Northern European social work practice. The discharge process, which is at the interface of health and social care can however be used as a case example of care management from the perspective of older service users and other key stakeholders.

1.4 Social work and its theoretical base - summary

A definition of social work from the International Federation of Social Workers, endorsed by the British Association of Social Workers is a helpful starting point:

'The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environment. Principles of human rights and social justice are fundamental to social work.' (IFSW, 2006:38).

Whether openly acknowledged by practitioners or not, there is a consensus (Payne, 1991) that the utilisation of theories is intrinsic to social work. Payne's model of administrative, therapeutic and collectivist model of social work (Payne, 1991) is seen as a useful construct for exploring practice, to which I will return in Chapter 10 in a discussion of the study's findings. Moreover to consider very briefly other theoretical trends of evidence based practice and post modernism, it is argued that paradigms which do not pay attention to the structural effects of health and social inequalities and globalisation, coupled with social work's role in corresponding discourses, run counter to the principles contained within the IFSW definition above.

There has been a growing realisation that social work in the UK has to look beyond the island's borders to learn from and join with international movements (Jones, DN, 2006). Clearly, globalisation has also meant that numbers of social workers and care workers coming to the UK from overseas are increasing, and vice versa.

It is suggested Payne's work on the 'knowledge base' of social work, and its relationship to other disciplines and other societies or cultures is also useful in terms of the connections between knowledge and practice (Payne, 2002). Payne asserts that the theory used by social workers is constantly being re-framed depending on experience, the situation and the user group and the perspective of the practitioner whether that be feminist, critical or psychodynamic. It is therefore useful to think in terms of knowledge 'biases' rather than bases and implies a sharing of knowledge or a blurring of boundaries with that of other professions such as occupational therapy and psychology.

From the arena of multi-agency practice the re-drawing of professional boundaries has led to a focus on new roles and skills. Preparatory work for the General Social Care Council in this area rejected health and business models of social care and social work (Blewett, Lewis and Tunstill, 2007; Duggan 2002). From this and other quarters there have been calls for change in response to the domination of the medical model in social care with adults. Furthermore an increasingly vocal service user movement has developed, that has called for a reconstruction of partnerships with users and carers (Beresford, 2007b). Lena Dominelli's definition sums up both in her outline of a 'relational' model:

'Social work can be defined as an exercise engaging with people to facilitate the telling of their story around a particular problem relating to their well-being, that is to articulate what has happened to them and why. Its interactive base makes social work a relational profession. In this practitioners and clients become co-participants in elaborating other narratives in which new possibilities open up.' (Dominelli, 2004:5)

After reading this positive view of social work interaction I sought to respond by seeking to find out if 'co-participation' could take place within a regime of hospital care management after 2004, when data generation began.

1.5 Social work, care management and the research study

In Chapter 2 (2.10 and 2.10.1) I trace the introduction of care management into social work practice in 1993, a fundamental paradigm shift from interpersonal

working with people to process management (Means, Morbey and Smith, 2002). Karen Postle's research on the operation of care management in two localities nevertheless found evidence of the *continuing* practice of interpersonal social work, as observed from and related by the participants in her study (Postle, 2002). My thesis considers whether Postle's conclusions could still hold and within the different context of hospital discharge post reimbursement, rather than community-based social work, with older people. Phillips and Waterson comment with regard to their research on care management and hospital discharge, that social work may take second place or:

'this traditional *social* focus of social work activity (recognizing and dealing with people's feelings) may not be there at all' (Phillips & Waterson, 2002:182).

As indicated, in addition to social workers and other professionals involved, the views of service users and carers, not explored by Postle in her 2002 research, form the basis of the current study. However, for the moment, we can turn to one of the hospital social work participants who echoed the views of many of her colleagues in the team where my project was based:

"I think that the speed of things and also the nature of hospital social work being fairly brief interventionist, unfortunately I don't think that we make our mark! I don't think that care management as a model has helped either, as it is very 'business' orientated and takes a systems approach, and I don't mean systematic! I think one has to work hard to find the time or environment or appropriate situation to be able to employ some social work principles." (S/W D)

Unknowingly that social worker's words also summed up my study's findings from the user and carers' interviews. Building upon Postle's work, in terms of this thesis' specific contribution to knowledge, I develop a description and analysis in Chapters 9 and 10 of:

- The hidden nature of parts of social work practice,
- How the more overt aspects of key social work tasks constitute a 'balancing' process, creating many tensions for the actors involved, and
- How these might be reconciled or accommodated as identified in the data.

1.6 Overview of thesis chapters

Chapter 2: Policy and practice contexts

This chapter not only sets the scene for the study by focusing on the social policy and the social work background leading up to 2003, the start of the project but also updates these areas looking at trends and discourses in health and social care. One of the dominant themes of the thesis is the tension between the two approaches and implications for service users, their carers and social work practice.

Specific topics selected from the above as most relevant to the thesis are: an exploration of the concept of hospital discharge and development of concerns for delays to transfer of older patients from hospital from 2000 as part of the so called 'modernisation agenda' leading to legislation in 2003. The aftermath of the latter is considered here, along with 'community care' and the targeting of services, user centrality and personalisation, concurrent performance and regulation of social care against a backdrop of diversity and inequality in British society. Finally, the history of policy development regarding informal carers, social work both with older people and hospital social work, are outlined followed by the development of 'care management', which was practised by social workers in the study setting.

Chapter 3: Literature review

Again this chapter begins by setting the scene for the study in terms of background literature of various types on older people, social work and hospital discharge published before, during and after the ending of the research project. It then considers relevant literature following the enactment of the delayed discharges legislation, involvement of older people in the discharge process, the contribution of social work to the latter and finishes by focusing on methodological issues.

In the conclusion to Chapter 3 I summarise the main themes found, and the gaps that the study aims to fill. Searching the literature on social work, older people and hospital discharge revealed very little that has been published on the topic since 2003. The large-scale reviews of research on hospital discharge and of outcomes, post-reimbursement nationally, made little mention of social work *per se* but were however from the older person's perspective (Social Care Institute for Excellence

[SCIE], 2006; CSCI, 2005), the balance being re-dressed somewhat by two research projects now published (Baumann et al, 2008; Hubbard et al, 2008).

Chapter 4: Methodology

Arguably the most important chapter in the early part of the thesis, Chapter 4 discusses the guiding, underpinning philosophy of the study, the methodological approach of phenomenology and research design which introduces the methods used to generate and analyse data in order to answer the research aims as above in 1.3. It then considers research validity and the ethical issues arising from the project: gaining informed consent and care of participants for example.

Chapter 5: Study locality and themes

Both policy developments and structures within the study locality and the process and progress of data generation are the subjects of this chapter. It describes the area in which the study hospital and local authority are situated and where participants live and provides brief background information on the hospital social work team, the local social services, the hospital and the performance of the local authority and the acute trust. The chapter then looks at how data generation from interviews and focus groups proceeded, from sampling and recruitment of participants to the handling of the data generated. The pitfalls and challenges encountered are considered, together with ensuing modifications to the research design and finally the approach to data analysis.

Chapter 6: Case example

An illustrative case example of a service user who left hospital provides context to data presentation at an individual level here. A discussion of the case study method introduces the chapter and the relationship of that method to the presentation of an illustrative case example. Before looking at fragments of data, their interpretation and organisation into themes, this illustrative case example aims to give insight into one person's, Teresa's, story. It was seen as being an opportunity to describe and discuss what it was like for individuals to come into, stay, interact with professionals and leave the study hospital to return home with support, as happened in her case.

Chapter 7: Themes of Loss and Transition

A short introductory section to the data presentation part of the thesis at the start of this chapter explains how interview and focus group data were organised into the themes that are the subject of this chapter and 8-9. The first of the collection of themes that emerged and were organised from the data generated from interviews with service users and their carers, were those around loss and transition. Service users talked about their lives prior to going into hospital and the circumstances of that admission whether this was due to a sudden episode such as stroke or heart attack or result of a more gradual deterioration in health or both. The impact of ill health upon lifestyle, families and loss of home for some are looked at along with emotional situations of bereavement, separation and adjusting to leave hospital and a different life very often afterwards. For some their hospital stay resulted in improvements, as reported in the final section, such as provision or increase in provision of social care services.

Chapter 8: Decision Making

Closely connected to knowledge of alternatives available to service users for post discharge care, either in an institution or back home are the themes about choices. Knowledge of the financing of care home places especially for relatives were discussed and how decisions were reached including use of planning meetings, home visits from hospital wards and the role of the hospital social worker in all this are explored.

Chapter 9: Relationships

The main aim of this chapter is to look at and discuss the role of hospital social workers from the perspective of service users, carers and other professionals within the study hospital. Hence it is formed of three parts with the first two drawing out the characteristics in the relationship with the social worker that were most valued, and ending with an important area of interest, i.e. how sensitive topics regarding the discharge process were approached and received. The third part considers constraints for professionals' work, aspects of inter-professional working, and service users' involvement in hospital discharge and staff attitudes to older people who wait on hospital wards for services. The chapter concludes with outlining differences between the perspectives and concerns of the three groups.

Chapter 10: Discussion of Study Findings

The penultimate chapter aims to draw together strands from the main findings, to examine what can be learned from them and implications for the study's philosophical approach, methodology, social work practice, social policy and service user knowledge. There is then reflection upon the meaning of the study findings for social work discourses and development of a theoretical model of hospital social work practice. Before concluding, the chapter focuses on the links with the study themes and national debates about the nature of social work.

Chapter 11: Conclusion

The scope of the research project and lessons learned in its execution start the final chapter, before turning to the uniqueness or originality of the study and how the research aims have been met. It then considers final issues from the study themes and areas for future research concluding with some recommendations for the practice of hospital social work in the future.

Appendices

The appendices commence with a personal statement and then include three further case studies that could not be incorporated within the body of thesis because of limit to the number of words. The case studies here along with the fourth in Chapter 5 are seen as both descriptive background on the context of the data generated on services users and carers and to illustrate issues discussed in Chapter 10. Copies of all written material relating to the research project such as interview agendas and participants' information sheets can also be found in the appendices.

1.7 Terminology used

The recruitment of participants for the research study is described in detail in Chapter 4. In essence a small sample of older people who had left hospital were interviewed. Their close relatives were also interviewed where appropriate and permitted. The former participants fall into the category I have chosen to refer to as 'service users' (represented by prefix **UO**1-19) with the latter as 'carers' (prefix **CO**1-16). Many of these relatives would not have described themselves as 'carers'

although most of them met objective criteria for the term. I merely employ the labels to distinguish one set of participants from the other and for convenience to avoid repeating lengthy explanations throughout the thesis. The adoption of the prefixes outlined, corresponding and references to the 'study hospital' rather than its name in the text is to ensure the anonymity given to all participants in my study. In using forenames as pseudonyms for participants I had not intended to show any disrespect and in fact I always asked participants how they would like to be addressed. Every single one of them preferred me to use their first name.

In order to meet the second project aim outlined in 1.3 regarding the examination of relationships between hospital social workers and other disciplines focused discussion groups were held with relevant professionals within the study hospital. Strictly speaking social service participants were officially entitled: 'care managers' but are usually referred to here as 'social workers' (**S/W** A-K) because that is the title that most of them insisted on using and is one that I prefer politically. For other professionals interviewed the prefixes are listed in 9.6.1 and for additional symbols used please refer to glossary.

1.8 Conclusion

This chapter has explained what has led to the identification of the research aims and the broad approach taken to achieve those. It has also touched upon influences shaping social work with adults up to 2009, most notably tensions between health and social care, resource shortages and managerialism. Other factors such as regulation and professionalisation are looked at in the following chapter. The literature and social policies referred to in the thesis will in the main start with the onset of 'community care' in 1990 up to the spring of 2010. However, prior to a review of the literature and a description of methodology, data presentation and analysis, we will turn in the next chapter to key concepts and crucial background policy developments in health and social care relevant to older people and hospital discharge.

2 National social policy and practice contexts

2.1 Introduction

This chapter will set the context of the study by describing and discussing the developments in social policy, social work and the NHS most relevant to the research topic. As in the literature review, except where it is of particular relevance to look further back, the intention is to restrict the historical scope of the chapter to post 1990, the point at which local authority social services were given the duty to assess for and provide social care in England and Wales.

The research study began in 2003; in 2009 there are 12 years of wide-ranging Labour government initiatives and legislation of relevance to my study to examine. Hence of necessity this chapter's description of policy can be but a brief overview of the background to fieldwork. Themes and trends most relevant to the thesis topic are presented instead of a chronological history. As has been observed 'fresh policies' have tended to add to rather than replace existing legislation and: 'have had to find space in a crowded policy arena that is often populated with competing imperatives and interests.' (Hudson, 2006:8). Furthermore there is a re-focusing of attention from delayed discharge measures since a flurry of activity in 2003, to the promotion of policies designed to prevent admission of older people to acute hospital wards. The impact of legislation to address delayed discharge in England was one of the original concerns motivating my study. Hence and because of its significance as background information for the thesis, the earlier sections of the chapter are devoted to it. Nevertheless it is possible that delayed discharge is in 2009 an issue of a lower priority for the government largely due to success in its own terms, that is a reported numerical reduction of such delays and a switch/shift to preventing hospital admission of older people and those with long term conditions (DH, 2005).

This chapter is also concerned with the development of social work with older people and the transformation of this branch of the profession into care management. From the social care perspective this is the story that influences the research, along with how the process of discharge is conducted and current influences upon post discharge services, including inequalities that persist in society and are reflected in social policy. The separate policies and perspectives for health

and social care, with overlap and tensions between the two, still exist in spite of repeated efforts at the margins and rhetoric from the government.

2.2 The role of hospitals and hospital discharge

2.2.1 Hospitals

Before considering discharge from hospital, I would like to briefly turn to the changing role of the hospital in the modern NHS, and wider society. Despite large investment in terms of resources, organisation and publicity in primary care, whose services impact upon a higher proportion of the population, hospitals still seem to be 'centre stage'. In the 'National Beds Enquiry' report of 2000, after reference to health care in a 'range of settings' it was stated: 'None is more important for public confidence than the hospital....' (DH, 2000b: 2). More recently the development of privately run treatment centres, and the proposal for increasing the numbers of 'poly-clinics' outside the hospital system, have caused public controversy. These and the past contested issues surrounding hospitals applying for Foundation Trust status and the use of private healthcare providers are also in a sense about hospital trusts' power to command and retain a monopoly of funding and their pivotal position in the community. Concurrently, the government has been promoting use of primary care facilities such as intermediate care or rehabilitation, to enable early discharge or avoid the use of hospital altogether, one of the aims of both the National Service Frameworks (NSF) for long-term conditions (DH, 2005) and for Older People (DH, 2001a). Finally, comments have been made regarding a future area for public sector savings in 2009: the yet more efficient use of hospital beds (HM Treasury, 2009). As an area of high expenditure hospital bed utilisation will probably always be subject to scrutiny.

2.2.2 Hospital discharge

Turning to people leaving hospital, until the late 1990's there was criticism by some commentators (e.g. Marks, 1994) of inadequate attention to discharge as a discrete process. The first turning point in this respect came following the introduction of 'community care' in 1993. As local authorities were given lead responsibility to fund and assess users' needs for care, government inspectors, academics and voluntary bodies were keen to check how well equipped they were for the task and to monitor progress of the new arrangements at the point of hospital discharge. Post 1997, the Labour government commissioned the National Beds Enquiry (DH, 2000b) and coupled with failure of trusts to achieve waiting list targets, this led to singling out

'bed blocking' for attention. Put simply, a plethora of studies of *delayed* discharge followed, looking for causes and potential remedies (Glasby, 2003).

Most authors assume an understanding of what is meant by a hospital discharge although some do pause to de-construct the concept (e.g. Jewell, 1993, Waters 1987). Proctor et al's research followed a group of patients at risk of an 'unsuccessful discharge'. (Proctor et al, 2001:208). In brief, it seems easier to elaborate on the former rather than find success in the area, although Bull and Roberts (2001:574) look at users' view of a 'proper discharge'. This is described as one which has maximum input to achieve a seamless transition to the next location, minimising the possibility of breakdown/readmission, and they identify three crucial 'circles of communication' (Bull and Roberts, 2001:574) to achieve the aim. The first circle comprises the various forms of communication between multidisciplinary team members. Secondly, communication between the older patient, their families and health care professionals about 'health status' is described. Interestingly social care, although it does feature in the paper, is not mentioned with regard to the model of 'circles'. Thirdly there is communication with 'community team members, depending on the elders' need for aftercare' (Bull and Roberts, 2001:574). From their data set four stages in the discharge process were identified from encouragingly: 'getting to know the patient' (p575), on admission through to 'making the transition' following the actual discharge to old or new location (Bull and Roberts, 577).

Both Neill and Williams (1992) report looked at as a 'landmark study' in the literature in the next chapter (3.2.2) and by the more recent *Living well in later life: A review of progress against the National Service Framework for Older Peoples Services* (CSCI, NAO and CHAI, 2006:43) suggest criteria for a 'good discharge'. The only point that the latter has in common with the former is: 'early identification of an estimated discharge date that is communicated to all key people' although this is obviously not the same as minimum of 24 hours notice for the older person recommended by Neill and Williams (1992: 82). Other criteria suggested by the NSF review are:

- Multiagency teamwork and discharge policy including NHS continuing care arrangements
- 'A single line manager or co-ordinator
- Early referral so that discharge planning starts as soon as possible

- Ward based co-ordinators to oversee the process for “simple” and “complex” discharges
- Active involvement of patients and cares in the planning and decision making process’ (CSCI, NAO and CHAI, 2006:43).

Clearly these points are more of a systems approach than Neill and Williams’ more personal ‘wish list’ as outlined in the next chapter (3.2.2).

Using Appreciative Inquiry methodology Reed and colleagues convened groups of users and practitioners and held individual interviews to start and learn from the positive aspects of hospital discharge, to enable professions to learn from each other and from users. Main themes on what constituted a ‘good discharge’ (Reed et al, 2002: 44) were identified by the researchers as follows: ‘understanding, co-ordination, empowerment and evaluation /feedback’. The latter refers to the ability to follow up and assess post-discharge (Reed et al, 2002:40). It appears that elements of both Neill and Williams and the NSF review appear in Reed et al’s formula.

Regarding the meaning of the concept of discharge for the key players involved, SCIE concludes from evidence in their systematic review that while hospital staff see discharge as the end of the process, the older person may view it not as an isolated event but as the start of something much ‘longer term’. This could be illness, disability, move to a care home or other changes requiring a readjustment of expectations and ‘life plans’ (SCIE, 2006: 47). More recently published research forming part of the NSF for Older People 2008 review, has been critical of the focus upon entry and exit points regarding older people’s experiences of the hospital system (Askham, 2008). This could bring us almost full circle to the past situation of an alleged lack of focus upon discharge as a process, as outlined in the first paragraph of this section (2.2.2) above.

2.3 Modernisation and delayed discharge

Delayed discharges or transfers of care as they are interchangeably labelled are now explored from a policy perspective. Delayed discharge was closely connected to the so-called ‘modernisation’ of social services from its inception. In 1998, the executive summary of Modernising Social Services includes a justification of why modernisation or radical change was required, because of ‘problems and failures’ in

social services. 'Co-ordination' was one of the six problem areas and specifically: 'Elderly people are left in hospital – so called 'bed blockers' while different authorities argue about who should pay for care' (DH, 1998:1).

2.3.1 History of growth in concern for delayed discharges

'Bed-blocking' however was neither a new concern nor a new term and was widely used in medical and social policy publications during the 1960's (Hall and Bytheway, 1982). In the jargon of the time, which still seems to have currency, the hospital was characterised as a system of inputs and outputs. Older people, who had no safe place to move to outside of the hospital, were therefore seen as blockages to the smooth running of the institution. Significant numbers also waited for places on long stay wards, which were provided then by the NHS, but there was not enough capacity to meet the need (Hall and Bytheway, 1982).

From the NHS's foundation it seems there have been disputes about where the responsibility for the care of older people should lie i.e. with health, or social services (Means, Morbey and Smith, 2002). A study of the records of Birmingham hospitals 1948 – 60 (Denham, 2006) revealed that older patients sometimes waited in hospital for up to three years due to a shortage of residential accommodation and domiciliary services so that older people became physically and socially institutionalised. Following an increase in numbers and lifespan, and therefore costs of hospital provision, coupled with changes to the role of women at home and in the workplace (Peace, 1986) the government eventually acted (Great Britain, *Chronically Sick and Disabled Persons Act* 1970) enabling local authorities to develop community alternatives such as provision of meals and day care. Growth in domiciliary care was also in response to the realisation that residential care was not the only option for older people, as had been seen from 1948 and earlier, i.e. apart from those looked after by informal women carers (Peace, 1986).

The 1980's nevertheless saw a huge growth in independent sector residential and nursing homes, which admitted many older people directly from hospital. The NHS and Community Care Act (Great Britain, *National Health Service and Community Care Act* 1990) was partly a response to what was viewed as burgeoning costs of this care. Health and social services were also expected to begin working effectively to achieve speedy discharges from hospital. Under the Conservative governments, once social services became responsible for arranging and largely funding long-term care in the 1990's, the focus was upon them to deliver satisfactory outcomes.

A series of inspections of arrangements followed and these are explored in the next chapter.

The Labour government of 1997 made manifesto commitments to improving the NHS, and specifically to cut waiting hospital waiting lists for hospital treatment. Under the NHS Plan of 2000 (DH, 2000a) funds were allocated to develop intermediate care and the following comment on the latter makes clear the rationale for this step:

‘This will not only improve the care of older people and contribute to the elimination of ‘bed blocking’. It will also enable the NHS to operate more efficiently by helping to release acute hospital beds. This should enable extra patients to be treated each year, contributing towards the targets on waiting’ (DH, 2000a: 15.15).

Clearly it can be argued that older people stand to benefit from treatment that is delivered quickly, but there has been an accompanying reduction in the number of hospital beds, together with a steady fall in available care home places (CSCI, 2008c; Laing and Buisson, 2005) and a rise in the population of older people, putting additional strain on the system (Mulley, 2006).

2.3.2 Prelude to the delayed discharge legislation

From 2000-2 progress on delayed discharge was not achieved as quickly as the government would have liked. There was reportedly an average of 7000 patients delayed in hospital per day in 2001 (National Audit Office, 2003). A great deal of attention was given to the subject including a number of research projects examining the reasons for delays which have been reviewed by Glasby, Littlechild and Pryce (2003). As outlined in the DOH discharge workbook, (DH, 2003a) delays to leaving hospital can be due in the main to:

- Waiting for NHS services
- Waiting for care home vacancies or domiciliary care
- Disputes with patients and/or relatives re discharge or plans for a move to a care home etc

Patients may also have waited on wards then for local authority funding for services and because of disputes about continuing health care responsibilities. There was much debate in the media about what was to be done and ministers hinted at more

proactive legislation to come based on Scandinavian models of fines for local councils. Glasby and Littlechild summarised the policy stages as follows (Glasby and Littlechild, 2004:56):

- 'Cash for Change (DH, 2001b) which became Access and Systems Capacity Grant for home improvement, community equipment, intermediate care
- Formation of Health and Social Care Change Agent Team in 2002 to work with agencies on the NSF implementation and on speeding up discharges
- House of Commons Health Committee (2002) inquiry into delayed discharges and National Audit Office report (NAO, 2003) on the subject
- Production of new Discharge from Hospital Workbook (DH, 2003a) tightening up discharge procedures'.

2.3.3 The Implementation of reimbursement

Following a Delayed Discharges grant to LAs announced in the 2002 budget, the Department of Health outlined the government's intentions for this additional pot of money:

'Councils will need to use these extra resources to expand care at home and to ensure that all older people are able to leave hospital once their treatment is completed and it is safe for them to do so. If councils reduce the number of blocked beds, they will have the freedom to use these new resources to invest in alternative social care services. If they cannot meet the agreed time limit they will be charged by the local hospital for the costs it incurs in keeping older people in hospital unnecessarily.'(DH, 2002a: 33)

The Community Care (Delayed Discharges) Act (Great Britain, *Community Care (Delayed Discharges) Act* 2003) finally came onto the statute book in April 2003.

Duties arising from the Act were:

- On hospitals to notify social services of older patients 'likely' to be in need of 'community care services' and their expected date for discharge
- A minimum period of two days for local authorities to assess and provide care services
- If the latter is not met acute trusts to cross-charge social services, but only if the delay is their responsibility at £100 per day or £120 in London and SE England.

In the Health Circular accompanying the legislation (DH, 2003b: 5), it is stated that it is 'part of the existing arrangements' including the NSF for Older People (DH, 2001a) which has the ending of age discrimination as one of its basic principles. The guidance to the delayed discharges Act (DH, 2003b: 5) claims that the 'policy is not age related' although it then states that the majority of those subject to long waits on hospital wards are older people, and has had the effect of being an ageist policy (Tanner and Harris, 2008). Furthermore it starts with the positive premise: 'a huge amount of work has been done across the country to improve people's choices and experience of care' (DH, 2003b: 5) which while may be correct regarding efforts made, understates the reality of the patchy provision of post discharge social care services for many older people at the time (Means, Richards and Smith, 2003). Some of the implications of the legislation as discussed in the literature are further outlined below and in the following chapter.

2.3.4 Progress since 2003

The level of delayed transfers of care of older people from hospitals was instituted as a target from 2002 for both acute hospitals and local authority social services. Following the reimbursement legislation (Great Britain, 2003. *op.cit*) and after delayed discharges began falling, the target to keep them at a 'low level' was imposed. Both the Healthcare Commission and the Commission for Social Care Inspection (CSCI) - now combined into a single body the Care Quality Commission - published annual figures as part of their performance target reporting. Table 2.1 below shows progress against the target numerically. According to the CSCI this represented a fall in delayed discharges in England to '27 per 100,000 population aged 65 and over in 2007-8 from 29 in 2006-7'. Furthermore 'averages for the different types of council for 2007-8 ranged from 25 for metropolitan districts to 36 for Inner London' with 'considerable variation between councils' (CSCI, 2008c: 78).

Table 2.1 Average weekly numbers of patients of all ages, whose discharge from acute hospital care delayed from 2003-2008 (CSCI, 2008c: 79)

Dates	Weekly average numbers of patients delayed in hospital
2003-4	3,640
2004-5	2,670
2005-6	2,410
2006-7	2,360
2007-8	2,190

The reasons for the delays in patients leaving hospital are broken down into categories in Table 2.2 below. Interestingly in the year 2007-8 the highest percentage of patients awaiting discharge were those waiting for non-acute NHS care. The figures show however that there was a substantial group comprising those awaiting assessment, although it is not clear from whom, and services funded and provided by local authorities.

Table 2.2 Reasons for delayed transfers of care for all patients in acute hospital beds in England 2007-8. (CSCI, 2008c: 80)*

Reason for delay	%
Awaiting completion of assessment	21
Awaiting public funding	4
Awaiting further Non-acute NHS care	26
Awaiting residential care	8
Awaiting nursing care	10
Awaiting care package at home	8
Awaiting community equipment & adaptations	3
Patients or family choice	16
Disputes	2
Housing issues	2
Total	100

****The numerator:** The average number of delayed transfers of care (all ages) in a week taken over the year from April 2007 to March 2008. A delayed transfer of care occurs when a patient is ready for transfer from an acute hospital bed, but is still occupying such a bed. A patient is ready for transfer when (a) a clinical decision has been made that the patient is ready for transfer AND (b) a multi-disciplinary team decision has been made that the patient is ready for transfer AND (c) the patient is safe to discharge/transfer.' (CSCI, 2008c: 80)

The human implications of the legislation including older peoples views and their involvement in the process are covered in the literature review Chapter 3. However a study in February 2007 of care of the elderly wards in an acute general hospital, followed a group of 158 in-patients over-65 years old from admission to discharge with the following results:

'36.7% (58/158) of patients had a delay in transfer of care. They tended to be older, had poorer pre-morbid mobility, and were more likely to be confused at the time of admission. Compared to the 2003 National Audit Report, a significantly higher percentage (29.3%vs.17%) awaited therapist assessments or (27.6%vs.9%) domiciliary care, with a lower percentage (< 1%vs.14%) awaiting further NHS care. Of 18 inpatient deaths, five occurred during the delay. Seven patients developed medical conditions during the

delay making them unfit for discharge. The number of extra bed days attributable to delayed discharges in this study was 682 (mean = 4.8) days'. (Jasinarachchi and Ibrahim et al, 2009: 1471)

The above suggests under-reporting of delayed transfers of care by 9.7% although these figures relate to two hospital wards over one calendar month rather than a national average calculated for England as a whole in Table 2.1.

2.4 Community care

2.4.1 Introduction

The greatest influence on public service provision and processes for older people and adult social work was arguably the enactment of the NHS and Community Care Act of 1990 (Great Britain, 1990. *op.cit.*). The Act laid down that social services were responsible for assessing, planning care and monitoring and reviewing services for all people in need of them in England and Wales. Although interdisciplinary working has added to or even altered social work practice depending on the locality, the 1990 legislation has remained in tact. It is therefore of major relevance to the thesis, providing the framework for the operation of care management in the study hospital and elsewhere. I would further argue that from 1993, hospitals had to wait for social care assessments, prior to discharge of vulnerable persons and that in itself was a major challenge for them. Delayed discharge legislation has returned power to hospital professionals in that they can compel care managers to assess a patient's needs within three days after receipt of Section 2 notification of fitness for discharge, or social services have to face the consequences (Great Britain, 2003. *op.cit.*).

'Community care' however was in part the product of, or it 'rode upon the wave', of a wider movement. Spearheaded by the work of Peter Townsend in the 1960s there began a campaign which criticised the conditions endured by older people in care homes (Townsend, 1964) and more widely by Erving Goffman (Goffman, 1968). This eventually blossomed into demands for the removal of institutional provision or 'warehousing' for all vulnerable groups. As with the introduction of the concept of personalised care from 2006, the community care reforms were universally welcomed in principle (Means, Richards and Smith, 2003) and positive aspects such as the centrality of the service user made it difficult for practitioners and others to criticise, that is until the full implications of 'care in the community' were unfolding.

2.4.2 Community Care Act

This legislation has already been referred to above in the context of hospital discharge and care home funding (Great Britain, 1990. *op.cit.*). This was an era of privatisation and 'marketisation' under the Conservative government (Means, Richards and Smith, 2002) in which there was compulsory competitive tendering for many local council services, an internal market for the NHS; local authorities were directed to use independent sector services for a proportion of domiciliary and institutional care and promotion of continued informal care giving at home (Means, Richards and Smith, 2003). For policy the end of the 20th Century was the beginning of a new era in terms of:

- Raising of the profile of adult social care, which since 1975 had been eclipsed by work with children and families
- User involvement in 'needs led' assessment and service provision although as has been pointed out power to direct both has remained with local authority staff.
- The rationing or restructuring of resources which has continued to the present day, has also meant that in spite of the above two points, actual care, particularly during night-hours, for older people in the community has been limited.
- Official demands for closer working arrangements between health and social care.
- The introduction of care management in the context of a split between purchasers and providers and local authorities as commissioners of care rather than direct providers themselves. The extent that this was embraced locally varied from one council to another.
- A mixed economy of domiciliary and institutional care with second and third sector providers has grown since then.

2.4.3 Assessment and targeting of care

Under the 1990 Act local authority social services became responsible for assessing needs of older and disabled people. For the first time the right of the individual to an assessment was enshrined in law (Lewis and Glennester, 1996). The policies have become amended since in that it became clear that a variety of professionals including therapists were duplicating those assessments. In the NSF for Older People (DH, 2001a) a Single Assessment Process using one document

was introduced, to be implemented from 2004. However it has been found that there has been considerable variation in: local implementation, the extent it has been embraced by all professionals and in the use of assessment tools (Askham, 2008: 32,40). In 2009 the Common Assessment Framework that is meant to encompass contributions from all statutory and voluntary agencies has overtaken this. Nine pilot sites are currently trialling the process (DH, 2009).

Undoubtedly spending on the NHS has increased, but social care has not benefited to the same extent (LGA, 2006). Research has shown that such a policy has left older people who are least able or motivated to complain, with unmet needs (Tanner, 2001). Moreover DH guidance such as Fair Access to Care (FACS) (DH, 2002b) which set out to standardise access to social care services nationally has had the effect of denying services to people assessed as having low or moderate needs in most local authority areas due to financial constraints. This policy has been under review (CSCI, 2008b). FACS together with a concentration on meeting complex needs has furthermore led to potential reductions in the quality of life for those older people ineligible for subsidised and /or locally commissioned domestic support (Clark, Dyer and Horwood, 1998).

While local authorities' funds for social care were under pressure, the NHS has continued retreating from providing health care as opposed to treatment for older people by re-drawing the boundaries of responsibility as summarised below:

‘the continued under funding of local authority social services in the face of rising levels of need. These needs are driven not only by demographic change, but also by the relentless withdrawal of responsibility by the NHS first from the heartlands and subsequently from the margins of long-term medical, nursing and personal care for older people’. (Glendinning and Means, 2004:151)

Pressure from various user and carer bodies and individuals mounted however regarding the inequities of FACS and the tightening of eligibility criteria. The CSCI carried out a review of the guidance and its effects. The subsequent inspection findings, in its publication ‘Cutting the Cake Fairly’ (CSCI, 2008b), included

- ‘An inadequate emphasis on human rights...
- People being assessed for their eligibility for services and /or being financially assessed before their needs are assessed...

- FACS is an explicitly hierarchical system, which excludes people from services' (CSCI, 2008b: 73).

At the time of writing, FACS guidance is still under review and the impact of the CSCI report and its recommendations on policy and practice are uncertain.

2.5 Personalisation and user/carer centrality

Another policy development affecting both older people and social work for that group has been the publication of the White Paper 'Our Health, Our Care, Our Say' (DH, 2006). This emphasises choice, independence, and extension of direct payments to personalised budgets for all user groups. Arguably the policy outlined below will have more impact upon older people in the community and the social work teams based there rather than their hospital counterparts and in-patients. As assessments and care planning have to be mostly achieved very quickly there is little room for painstaking setting up of personal budgets and employment of home care support via direct payments. The literature review in the next chapter considers choice for older people leaving hospital in general. The White Paper is notable for what it does not specify about social work and future roles apart from references to care navigation and brokerage (Hudson, 2006).

The following are the key parts of the White Paper:

- Health care closer to home including practice based commissioning by GPs
- Integration of services
- Access to information
- The expert patient programme, life checks and self-care
- Direct payments extended to individual budgets across the range of local authority and equipment services.

The first three points clearly link in with the thesis topic and specifically multidisciplinary working and the current aim of treating older people away from an acute hospital setting. In fact officials were explicitly referring to an 'out of hospital' white paper prior to publication allegedly (Glasby, 2006). Furthermore Bob Hudson commented that 'no new money' was available to fund the above aspirations. He also identifies five policy dilemmas inherent in the White Paper:

- 'Community versus secondary services
- Social care v health care
- Cost containment v user led outcomes
- Partnership working v organisational self interest
- Coherent governance v market freedom' (Hudson, 2006:8).

There has been a mixed reaction to the legislation as indicated. Some commentators have broadly welcomed individual budgets for most users with some reservations for their practicality for older people (Glendinning et al, 2008) while others have been concerned about the growing individualisation and fragmentation of social care. Arguments concerning the latter tend to focus on the urging of service users to seek private or individual solutions with uncertain impact upon user groups and individuals who may find themselves further isolated and with less power (e.g. Scourfield, 2007; Dustin, 2008).

Government publications in 2009: 'Building a Society for all Ages' – their strategy on ageing and 'Shaping the Future of Care Together' the long awaited Green Paper on Social Care continue to develop the themes outlined in this section. At the point of publication these documents are consultative, the proposals arguably aspirational with no new money attached and with the 2010 coalition government's approach unclear.

2.6 Performance and regulation

In 2008 an accompanying strategy for the adult social care workforce to 'Putting People First' (DH, 2008b) was issued with the following main elements all of which have relevance for social workers in the study hospital, the second and third points in particular:

- A skilled workforce with training for social care organised under the auspices of Skills for Care and post qualifying social work education under the General Social Care Council (GSCC)
- Working across boundaries
- Managing risk
- Working in partnership with the community.

In its commentary on the above 'concordat' the GSCC identified social workers fulfilling 'support, brokerage and advocacy' roles.

The National Skills Academy for Social Care has since been instituted directed at social care leadership with a world class commissioning brief in addition to recruitment and retention, support of staff and the raising of the status of social care. At this point it is premature to assess the impact of the Academy, which is still in the planning stages (Skills Academy for Social Care, 2009). Almost concurrently, the latter's establishment is running counter to a campaign of vilification of social work in the media and reviews of child protection social work in response to deaths of infants in families with social workers. While social work with adults has for the most part escaped negative media attention the national high profile scandals have cast shadows over the whole profession. At the very least it is likely that children and families' work will be given even greater resources which could leave less for other groups during the forecasted public spending cuts to local authority budgets. The section on diversity and inequality below also looks at older people's share of national expenditure.

The Commission for Social Care Inspection (CSCI) has operated since 2003 and merged as part of the Care Quality Commission (CQC) with effect from 1.4.09. The CSCI carried out annual inspections against targets and grading of care homes and domiciliary care agencies as well as of social services. In its last annual overview of social care CSCI found a 'steady improvement in the overall performance of councils over the last 6 years' but has concerns for the future of people with multiple and complex needs, self-funders and access to 'lower level' services which maintain independence and improve the quality of life for older people (CSCI, 2009a). Likewise the registration of social workers which is gradually being extended to registration of the whole social care sector by the GSCC, is clearly a major first step in safeguarding users in the own homes and care homes.

The importance of CSCI's and now CQC's work in assessing performance of social care with visible outcomes in terms of ratings of services and institutions while involving users and responding to public concerns should not be minimised. The adoption of targets such as star ratings has been criticised however (Tanner and Harris, 2008) as being onerous and somewhat crude and in its final year the CSCI have consulted on new ways to measure performance, which is now against the main principles of caring (CSCI, 2009b). It would be interesting to gauge how much use users and carers do make of the Care Quality Commission's on-line information. It has been pointed out that older people for a variety of reasons

including low incomes have fallen behind other groups in society regarding use of computers and on line information (Capel et al, 2007). Nevertheless conventional wisdom dictates that it is likely that such use can only increase, as the general public – as long as they have computer access - grow more familiar and confident with searching the Internet, from schooldays onwards.

2.7 Social care integration and funding

Having exhorted health and social care to work closer together for at least 30 years the Labour government has taken steps to require councils and Primary Care Trusts to pool social care budgets and commission jointly. The extent to which structural and professional barriers can be overcome and how far integration is of benefit to service users and carers remains contested (Huby et al, 2007).

Of particular relevance to older people leaving hospital, is how they can pay for domiciliary and institutional care. In 2001 the Government announced the payment of a contribution towards the nursing element of care home fees (National Archives, 2010). Action has also been taken since the research study began on standardising continuing healthcare funding as it was recognised that access to this important funding stream was restricted and difficult to apply in many parts of the country. Progress on actually improving this and long term financing of social care has so far been slow. Following the Royal Commission of 2004 recommending free personal care for all in need of it, Derek Wanless published the report of his investigation into the situation in 2006, again critical of inequity in the system (Wanless, 2006). In June 2008 Gordon Brown as the then Prime Minister re-opened the debate for the Government, heralding the forthcoming 'Care and Support' green paper (www.number10.gov.uk/Page15497). Pressure groups have demanded legislative action as a matter of urgency and the Joseph Rowntree Foundation has called for interim measures to remedy the unfair system of social care charges that have to be met by service users and/or their families (Collins, 2009). This question has been addressed albeit speculatively in the Social Care Green Paper referred to in 2.5.

2.8 Diversity and inequality

The above points link in closely to views about older people's spending on social care and this is part of the backdrop to my thesis and the wider concerns about the position of all vulnerable or so called 'economically inactive' citizens in capitalist, globalized societies. As discussed there are additional implications for social policy and the budget for welfare arising from recession from 2008. The situation of even

wealthier older people, who live off superannuation, savings or investments, when interest rates have dropped to below 1%, is causing anxiety.

In terms of healthcare three quarters of NHS clients are over 65 years of age but total expenditure on this group amounts to but two fifths of the total budget (Help the Aged, 2010). Tanner and Harris point out that disabled ex-service personnel were prioritised for post-war social services and that provision for disabled people was and has remained more generous for disabled people (Tanner and Harris, 2008). Hence the Independent Living Fund and the mobility component of Disability Living allowance can only be accessed by those under-65 years old.

2.8.1 Health inequality

Research following up the outcomes of five years of the NSF for Older People 2001 looked at 16 projects in England and progress against six principles underpinning the framework, one stating that 'there should be no discrimination in health and social care services'. In the words of a commentator on the review:

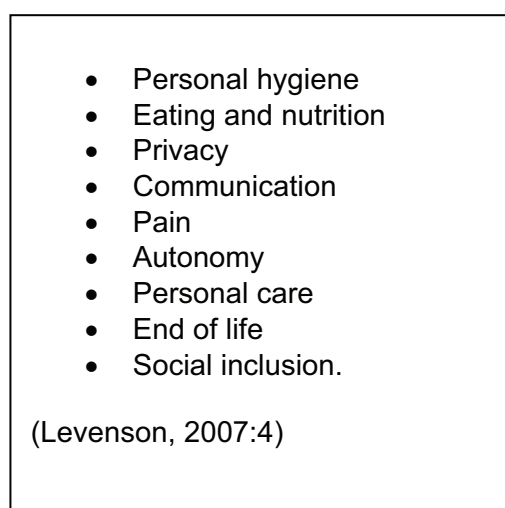
'The projects demonstrated the tension between a positive view of the ageing process and the perception of old age as a period of decline. There was evidence from some studies of ageist attitudes and stereotypes among service providers and of age and cultural discrimination' (Petch, 2008:37).

In spite of older people's reported satisfaction with hospital care (CHAI, 2007a), there have been yet more scandals and concern about the treatment of older in-patients: principally undercover snapshots of poor nursing practices (Doward, 2005) and accounts of sub-standard care in general (e.g. Skellington, 2008). In 2007 there was also a report of low standards of nutrition for older people (CHAI, 2007b). Cleanliness and hygiene in hospitals meanwhile continue to be important issues and popular topics in the media with the emergence of Clostridium Difficile (Cdif) as a problematic, potentially fatal, infection in 2007, in addition to that other 'culprit' MRSA. The Department of Health pledged to tackle hospital acquired infections and progress has been reported regarding a reduced prevalence of Cdif (Office for National Statistics, 2010). Hence it is often argued that older people should pass through hospitals as quickly as possible, in order to avoid undue exposure to such diseases. Nevertheless, it has also been pointed out, by a British Medical Association spokesperson, for example, that rapid turnover of patients does not allow for full cleaning of beds and surrounding areas, which has to be balanced against achieving the 18-week waiting list target:

‘The target has been to get patients through as quickly as possible rather than looking at cleanliness and the quality of the care, sometimes that they are having. What you measure is what you get – the government are focused on speed and getting patients through rather than that quality and cleanliness.’ (Fielden, 23.9.07).

To counteract the physical treatment, conditions and attitudes towards older people receiving health and social care, the DH launched the ‘dignity in care’ campaign (DH, 2008a). The organisation Help the Aged reviewed progress against the principles of the campaign as outlined in Figure 2.1 below. Their policy director also commented:

‘We seem currently to be stuck in a cycle in which the occasional tabloid horror story triggers outraged comment, popular revulsion, campaigning challenges, political ‘back-foot’ reaction, but little sustained attention to improvement.’ (Paul Cann, Director of Policy and External Relations, Help the Aged in Levenson, 2007:5)



**Figure 2.1 Domains framework for understanding ‘dignity’,
Help the Aged**

In 2009 at the time of updating this chapter Stafford Hospital received a very critical inspection, specifically concerned with higher than average number of deaths, and poor nursing practices, with patients’ dignity in care clearly not preserved. A crucial part of my study is to report on older people’s experiences of their care within and out of hospital.

2.8.2 Needs of black and minority ethnic groups (BME) elders

In 2008 the CSCI published research as part of the Putting People First agenda on BME elders and younger disabled people's experience of social care (CSCI, 2008a). While those they interviewed responded that they would recommend a service to others half of the group of 60+ reported that their specific cultural needs had been considered during assessment and over half reporting direct or indirect racial discrimination. Expectations and level of intent to complain were also low. Only 37% of social care services had acted to address racial equality and services for BME older people were not always available or they did not always want to use them. Personalized services, choice and appropriate information needed addressing at policy and practice levels, the authors concluded (CSCI, 2008a).

2.9 **Carers**

Without informal or unpaid carers, 'care in the community' could be virtually non-existent. The importance of carers to older people, and in particular those leaving hospital, cannot be over emphasized, hence their inclusion in my study's investigation. The aim of this section therefore is to highlight some major policy issues and developments for carers in England and Wales.

The contribution of carers to health and social care has only been officially recognized in policy and statute since the mid 1970s. Prior to that, the duty of women especially to care for relatives and neighbours had been taken for granted but became exposed as more women had to work full-time. Carers themselves, and the women's movement mounted campaigns, research was commissioned and eventually the government took some limited action in terms of policy recognition and welfare benefits (Lewis, 2006).

Carers of all groups requiring health and social care have been entitled to separate community care assessments since 1995 (Great Britain, *Carers (Recognition and Services) Act 1995*), the Invalid Care Allowance since 1986 (single women carers from 1974) and respite or breaks from caring since 2004 (Great Britain, *Carers (Equal Opportunities) Act, 2004*) and the DH monitors local authority compliance and progress. Carers UK continue to draw attention to unpaid caring and the lack of recognition for carers' individual needs. Furthermore there are specific concerns regarding older and BME carers. Research for Carers UK found in 2008:

'Ethnic minority carers were especially likely to say they felt restricted in using services because they lacked information, or because services were too expensive, lacked flexibility, or were not suitable for their individual needs. Our interviews with ethnic minority carers raised some issues about the skills of paid care workers, especially where service users spoke languages other than English, and about culturally appropriate provision. In general, however, common issues were more important than differences' (Yeandle et al, 2008: iii-iv).

A research study carried out by Sheffield Hallam University for Carers UK reported in 2005 that there are: 'over 1.5 million people aged 60+ providing unpaid care': 'over 8,000 carers are aged 90+' and '4,000 of these very aged carers provide 50 or more hours care each week.' (Sheffield, Hallam University, 2005:2). The study found some disturbing features about the cohort of older carers, estimating that one in five women and one in six men aged 60-64 had caring responsibilities but in addition many were in poor health, some still worked and they were concentrated in areas of poverty.

A longstanding issue for carers has been availability of the appropriate support for them enabling their own needs to be met and also that might include covering domestic tasks or personal care and choice of times that is provided. As local authorities have retreated from arranging and funding domestic support in many areas, carers have been affected alongside older service users (Clark, Dyer and Horwood, 1998). Some carers choose to give personal care to close relatives, and indeed this may be preferred by the user rather than receiving care from a stranger, with the backup of outside help to carry out other household duties. The extension of direct payments to carers of disabled children and adults can provide greater flexibility and choice as to 'who does what kind of caring' and domestic tasks, although eligibility is established via a community care assessment (Clark, Gough and Macfarlane, 2004). Carers UK in their information web pages encourage carers to consider the use of direct payments to meet their own wider social needs e.g. to pay for counselling and leisure classes (Carers UK, 2009).

'Putting People First' (DH, 2008b) as referred to in 2.6 above, the blueprint for transforming adult social care, set out its vision of: 'A personalised system, which... is on the side of the people needing services and their carers' (DH, 2008b: 1). The policy set out the deadline of April 2011 for every adult eligible for non-emergency community care services to have an individual budget and be able to commission their own services. Many commentators however believe it is unlikely the target will

be met. Moreover in partnership and collaboration with all sectors of health and social care, carers are meant to be equal experts: 'real change will only be achieved through the participation of users and carers at every stage.' (DH, 2008b: 1) i.e. nationally, locally and at the level of the individual seeking services. In a briefing paper on personalisation co-produced with Carers UK, SCIE describes personalisation as having the potential to improve type and flexibility of care for service users and therefore impacting on carers but also for carers to commission their own tailor made support (SCIE, 2009). This includes 'life beyond their caring responsibilities' whether that is in employment, leisure or education. Crucially carers should be able to access support for managing finance and care components of an individual budget and not be left being fully responsible with more onerous tasks than if a local authority were directly providing the service (SCIE, 2009).

The DH commissioned research into the outcomes for users and carers in the 9 individual budget (I.B.) pilot sites and reported that these were mostly favourable for both groups (Samuel, 2009). However in their paper considering the impact of I.B.s upon carers, Clements, Bangs and Holzhausen (2009) also looked at that DH study's findings with different conclusions. They argue that in the pilot sites and as new systems for I.Bs are rolled out nationally, carers could be rendered 'invisible'; separate carer's needs assessment might not be offered; and often the basic right of a carer not to take the caring role whether that be due to health or personal circumstances can be overlooked. In common with all policy initiatives, resource constraints can influence fine principles as outlined above (Clements, Bangs and Holzhausen, 2009). It is probably too early to fully assess the overall gains or otherwise for all carers with access to personal budgets and clearly that is influenced by public spending in this area.

In 2008 the Government published the National Carers Strategy (DH, 2008c) making £150 million available for Primary Care Trusts (PCTs) to spend on short breaks for carers. Research commissioned to review the implementation of this strategy however found that four fifths of the money allocated to PCTs for carers' respite was not used for that purpose in 2009 -10 (Gillen, 2010). The money had not been 'ring fenced' but: 'Where PCTs did pass on funds it has made a crucial difference' (Gillen, 2010). For the period 2010-11 strategic health authorities had been asked to monitor PCTs commissioning of short breaks for carers. Since then, following the May 2010 election and the installation of the coalition government - although a review of and consultation for the Carers Strategy has been announced -

the very future of PCTS is in doubt, so that it is not clear what will happen. Furthermore cuts in the spending of local authorities and on welfare benefits across the board, impacting on most of the subject matter in this chapter appear imminent at the time of writing.

Hence in summary, the discussion of and focus upon issues that are of most relevance and importance to carers has changed in policy terms since the 1970's. Early debates looked at recognition for those who had for centuries undertaken informal caring of sick and disabled adults and children as 'carers', which led to state provision of a small income and welfare benefits. The right to a carers assessment of need was initially largely about respite or short breaks but this has been reframed in principle to encompass the broader social needs of carers as individuals, now seen in theory as expert partners in care. The varied requirements of carers from diverse backgrounds and ages caring for those with differing mental and/or physical conditions has also been raised mostly by carers voluntary organisations. Finally under the personalisation agenda carers have emerged as both recipients and managers, albeit with support, of individual budgets for their own and service users wellbeing. It will be interesting to look at the concerns of carers in my study, whether they in fact see themselves as informal 'carers', if they believed that they had a choice in taking up the role and whether they have been offered either assessments of their own needs and direct payments, for instance.

The next chapter refers to literature on the role of carers in hospital discharge, in 3.3.2.

2.10 Social work with older people and hospital social work

Looking at social work practice as examined in the thesis, the model I employ to explore the kinds of social work that might be practised is Payne's triangle of administrative, therapeutic and collectivist social work (Payne, 1991). He has also shown how the model represents the strongest traditions intertwined in the profession's foundations and development. It has been suggested that 'there has been relatively little history of the use of any approach to social work [with older people] other than *administrative*' (Lymberry, 2005: 53). However this statement is somewhat reductionist considering the complexity of social work's history, its connections with both health care and the community.

Regarding Payne's "collectivist" social work, its close relation - community work, flourished from the 1970's to the 90's and still does in parts of the country, usually sponsored by the voluntary sector (Tanner and Harris, 2008). Although it is possible to argue that community work is not the same as social work, and it has been associated with other age groups, there are close links between the two and many community projects are inclusive of all age groups often depending on older people for key administrative functions, as contributors as well as service users. An example of this would be the large numbers of lunch clubs nationwide, run for older people but most dependent on senior citizens' voluntary help.

Focusing on **social work with older people in the community**, Ric Bowl wrote about the low status that social work with older people had both for services and for social workers, in the 1960's and 70's. His description of administrative type tasks however, resemble contemporary care management activity:

'Social work for these older people consists of the mobilisation of practical services and any prolonged contact with a social worker is dependant on the time taken to mobilise the resource' (Bowl, 1986:129).

This approach to social work with older people was based on the 'ageist assumptions: that their needs are routine' and furthermore that they therefore merit intervention from largely unqualified staff (Richards, 2000: 38).

Hospital social work's origins - its association with scientific treatments and financed at one time by hospitals, are well known. A different, more mixed model emerged to that governing welfare visitors inhabiting post war social services as described above. Mary Stewart, is reported to be the first 'lady almoner', employed at the Royal Free Hospital in 1895 to make sure that hospital care was only provided to the genuine, deserving poor (Badawi and Biamonti, 1990). In the realisation of the effects of poverty upon families Mary Stewart applied casework principles and I believe did try to help them. From then on it appears that there were twin strands of administrative and therapeutic approaches to social work at play. In 1945 with the founding of the NHS: 'medical social workers were in hospitals, their role extended to providing funds from charities, to assisting patients with a wide range of problems' (Penhale 1997:47). In fact in my first position as a hospital social worker in 1979, i.e. post- Seebohm re-organisation, I replaced a much-respected white-coated almoner, who used to wait in her office for young women to be sent round from outpatients to discuss their pregnancies.

Furthermore in the parallel setting of the hospice, therapeutic social work has been carried out for many years in palliative care (Beresford, Adshead and Croft, 2006a).

Community social work, and hospital social work with older people - aside from some specialities often employing social workers jointly with charitable funding such as HIV, renal units or oncology - came under the one umbrella of care management in the 1990s. In more recent studies the care management model as discussed below was seen as constraining hospital social work from providing a 'therapeutic or helping' service (Connor and Tibbit, 1988; Penhale, 2000). Discharge planning was viewed as a 'new emphasis' operating 'at the expense of counselling people with serious health problems and their families' (Penhale, 2000).

As outlined above the care management model of social work as laid down in the guidance of the NHS and Community Care Act 1990 (Great Britain, 1990. *op.cit*) was based on the work of the pilot projects in Kent and Gateshead, evaluated by the Personal Social Services Research Unit (Challis, 1998). The original idea of case management was American in origin and critics of the system have pointed out that care services are very different in North America than in the UK (Means, Richards and Smith, 2003). Furthermore the pilot projects were actually reported to work well with social workers as budget holders carrying a small caseload of adults with complex community care needs. The subsequent reality for those social workers that operated the model in practice was often far from this one and is discussed later in the thesis

2.10.1 Social work and care management

Another contested area of debate surrounding care management is its relationship to social work, and is a matter of great interest to me and was a key impetus for conducting the study. The views on this subject seem to fall into six broad categories:

- Care management as a new social work method it has been argued cannot be merely treated as such and divorced from the societal context of operation (Petch, 1996, Sheppard, 1995)
- Some research has indicated that social workers operate in highly individualistic ways interpreting care management as 'street level bureaucrats' and not necessarily as stipulated by the DH or their own management's guidance (Baldwin, 2000)

- Largely due to the emphasis on consumer involvement some writers regard care management as having great potential or opportunities for positive social work intervention (Hardiker and Barker, 1999)
- Similarly, there is a school of thought insisting that social work skills, particularly those involved in assessment and monitoring functions are fundamental to the operation of care management. (Kerr, Gordon, MacDonald et al, 2005, Barnes and Walker, 1996)
- Some see that the bureaucratic nature of care management is too restrictive and its administration too time consuming for the 'proper' practice of social work (Allen, Hogg and Peace, 1992; Lymbery, 2005).
- The administrative and perhaps the most controversial view of some employers was that care management could and has been carried out by nurses and therapists as well as by qualified social workers (McDonald, 1999).

The particular role of social work or care management in the hospital discharge of older people in the literature is discussed in the next chapter. It is looked at again in relation to the findings of the study, Payne's theoretical construct and the latest developments in the profession since the research was completed, in Chapter 10.

2.10.2 New roles for social workers

The GSCC argued that social workers were 'ideally fitted' for new roles regarding individual budgets including brokerage, advocacy and navigation (GSCC, 2008). Others have seen that an opportunity has been missed to present a holistic model of health to encompass the importance of the social and supportive relationships, including access to community networks that can be facilitated by social workers (Beresford 2007a; MacLeod et al, 2008).

The difficulty for practitioners and champions of user empowerment to express reservation of the largely untried model of individual budgets was commented upon (Scourfield, 2007). This is in the context of the knowledge that a highly supportive infrastructure is needed (Glendinning et al, 2008), and as with choice of hospitals, GP practices and so on, many older people may prefer not to choose and employ staff, but to have high quality/flexible social care (Land, 2006). New skills of brokerage and budgeting required for care managers will impact upon social work

education and training as well as the interests and expertise of potential recruits to the profession, and more importantly upon service users:

‘a brokerage model overlooks the skill and complexity of the social work task and its potential to work in ways that can challenge users’ disempowerment’ (Postle and Beresford, 2006:232).

The national review of social work received little publicity and described a wider vision for social work (GSCC, 2008 & 2007). The review’s evidence particularly with regard to the aspects of social work valued by service users can be considered there as useful comparators to the findings of my study which seeks older people’s experiences of social work.

2.11 Conclusion

The period of social policy regarding older people since 1997 is now characterised by individualised person-centred care and localism in tandem with national standards and regulation in a context of continued under funding of social care. While efforts have been made to tackle ageism, the needs of carers and inequalities for BME groups, research have shown that there is room for major improvement in all areas. Although there has been a plethora of policies and guidance on health/social care there has been no decision so far, only some proposals for discussion, on the huge question of long term care financing for individuals. Social care under-funding and rationing has continued – in contrast to spending on NHS to a greater extent. Contradictions have ensued and some ‘unintended’ consequences of policies in the case of FACS process for example, affecting older people’s ability to maintain independence with little access to ‘low level’ care. It has also been argued that a focus on older people leaving hospital has diverted resources from preventative work (CSCI, 2005).

For practitioners the milieu within which they operate are perhaps best portrayed as fast moving, shifting ‘sands’ of which only a part has been captured within this chapter. The researcher has difficulties too in that while analysing the effects of policy, that policy and the issues surrounding it have changed before the ‘ink on the page has dried’: ‘policy may change emphasis during the course of the research meaning the results answer yesterday’s question.’ (Petch, 2008: 37).

Substantive policy tensions or dilemmas within policies and most relevant to thesis include:

- Delayed discharge legislation can be viewed as ageist in only targeting the over 65s but the original claims were to protect older people, from hospital acquired infections and waiting around in poor environment of a hospital ward with danger of institutionalisation. However, older people are surely entitled to the best and most appropriate treatment whether in hospital or a community unit. The impact of the delayed discharges legislation upon social services and older people in terms of staff attitudes, relationships and morale is looked at further in the next chapter. There are four main perspectives on discharge running through the thesis with tensions between them:
 - From the government regarding *numbers* of older people delayed, contributing to NHS costs and affecting waiting lists for admissions
 - A purely health model of *physical fitness* for discharge
 - Psycho/social perspectives, which look at the person, holistically, how they relate to their physical state and environment and family or other networks
 - Managerial perspectives which focuses on hospital as a system of inputs and outputs, concerned with turnover
- Health funding for social care retreating, putting additional pressure on social care and perpetuating territorial disputes around issues such as whether bathing is a health or social care need.
- Arguments about the benefits of community care. Needs led assessments have been promoted but limited budgets to meet those needs.
- Registration and protection of social work title, raising the status of the profession but some argue while they increase safeguarding for service users, distance practitioners from service users.
- Personalisation of care while a positive step for some older people but negative effects of individualised budgets for both service users *and* non-local authority employees with lack of access to training, support and trade union membership
- Performance management may have raised some standards but as this chapter has indicated there are still examples of lack of dignity in caring and mechanistic care management obliged to tick boxes for assessment, monitoring and reviewing.

Hospital discharge mechanisms may have become more efficient but the question remains – is the way the process operates suited to the needs of many older people, particularly the oldest or frailest patients. It is not working well for older people, their families and carers if they have to be re-admitted to hospital and the decision-making is rushed/non-empowering as reported in the literature in the next chapter (e.g.CSCI, 2005). Policy themes of multidisciplinary working, person centred care or user centrality and the development and effectiveness of care management in the hospital setting have all been raised in this chapter and are further explored with regard to the literature on the topics, in the chapter which follows. The picture of how staff worked locally, the structure and assessment of services are described in Chapter 5.

3 Literature review

3.1 Introduction and scope of review

The aim of this chapter is to present an overview of the literature regarding older people's experience of hospital discharge in the UK and of social work in that context. Given the interest in the topic area shown by policy makers and commentators, there has been a large volume of output from all the disciplines and institutions encompassed by health and social care, just on hospital discharge for older people. In order to select literature that is most relevant to my study, this review focuses on research that looks at the older person's experience of hospital discharge and the role of social work in the process. It seeks to identify the substantive issues and some of the gaps in the literature that this study aims to address.

Regarding the impact of policy and research upon service delivery there is clearly a link with the previous chapter, which included discussion of some of the research and commentary leading up to the delayed discharge legislation of 2003. Hence reference here will be made to some landmark work pre-1990. Otherwise the literature looked at will be from the 1990 Community Care reforms onwards (Great Britain 1990. *op.cit.*), from the point when social services departments were given responsibility for the care management for adults: that is assessment of their social care needs by care managers who were mostly but not exclusively social workers and the funding and provision of 'packages of care'. Social and health policy as well as political concerns such as delivering care in the community within budget, consumer choice and addressing delayed discharges are reflected in much of the material reviewed.

Exploration of the effects of the introduction of the delayed discharges legislation (Great Britain, 2003. *op.cit.*) as already discussed was an impetus for conducting my study. There were two investigations of older people's experience of care management prior to that event of 2003 that impressed: Stanley, Reed, and Brown's work (1999) and that of Phillips and Waterson (2002), who with regard to transfers from hospital to care homes concluded:

'The reality is that there is an explicit *social* task for social workers in buffering users and carers from pressure to move inappropriately and too quickly' (Phillips and Waterson, 2002: 183).

Both research projects used qualitative, interpretative approaches and conducted interviews with staff and older people and their carers. To locate my study, it was inspired by these examples and aimed to build upon aspects of the work.

Following a general discussion on the literature search, the background literature is explored including government reports, before focussing on the areas that are most relevant to my study:

- Post-reimbursement literature
- Involvement/participation of older people
- The contribution social work to the discharge process

Methodological issues and gaps in the literature are identified before concluding with an overview of the chapter's key points.

3.1.1 Literature search: methods and sources

The body of research and other published material on 'hospital discharge' are vast and originate from all the disciplines involved. The majority of references found have been to literature from the nursing perspective, followed by social work/care and occupational therapy.

Following Brian Taylor et al's approach (Taylor, Dempster and Donnelly, 2003) relevant databases were searched for social work research: Medline, CINAHAL, Caredata and ISI Web of Science to look for texts on social work and hospital discharge of older people, the focus of this study. As the subject is taking the older user's perspective the latter and related terms such as elderly/aged people, elders, user satisfaction/involvement/consultation, patients' views, consumer participation and hospital/social work/care management, discharge/transfers of care and all combinations/permutations were sought. Confirming the advice given in Taylor et al's paper, a considerable amount of material that has not shown up on the above databases was located via a 'citations trail'. In addition the following journal contents pages were 'manually' searched:

- British Journal of Social Work
- Health and Social Care in the Community

- Journals of: Interprofessional, Integrated Care, Advanced Nursing, Nursing Research, Health Services and Social Work
- Age and ageing
- Ageing and society
- Community Care.

Websites of the following organisations were viewed regularly to keep up to date with their publications:

- DH
- Social Care Institute for Excellence (SCIE)
- CSCI and Healthcare Commission, now Care Quality Commission
- Age Concern and Help the Aged (now combined into Age UK)
- Carers UK
- Joseph Rowntree Trust
- Kings Fund
- Centre for Policy on Ageing.

In summary, the literature on hospital discharge can be categorised into 4 main types:

- Government departmental inspection and guidance, including promotion of 'pioneering' practice by the Change Agent Team
- Research and commentary from independent bodies
- Peer reviewed academic research, including journal articles and theses
- Practice textbooks and 'grey' literature from both paper publications such as locally commissioned but unpublished studies, newspapers and web pages.

3.2 Background literature

3.2.1 Review of reviews

There are three useful literature reviews of hospital discharge and older people (Taraborrelli, 1998; Glasby, Littlechild and Pryce 2003, SCIE 2006); although Glasby et al's systematic review is on the subject of 'delayed discharges'.

Surprisingly the SCIE systematic review (SCIE, 2006) is not of great assistance to the social work practice element of the current study, in spite of SCIE's role being stated as:

‘to improve social care services... by identifying good practice and helping to embed it in everyday social care provision’
(www.scie.org.uk/about/index.asp, 2001).

While older peoples experiences are of paramount importance in the SCIE review (SCIE, 2006) and commendably only research which directly sought their views of discharge was eligible for inclusion [28 out of a possible 104 studies] in 51 pages there are just three mentions of social workers, all from the one paper in relation to discharge to care homes (Reed and Morgan, 1999). The role of domiciliary care and care home personnel does not feature at all. ‘Staff’ are referred to throughout in general but while acknowledging how older people in this stressful context value ‘discussion with a social worker’ (SCIE, 2006: 42) the review adheres to its remit without making any concluding recommendations for care management/social work policy or practice. Practitioners may not find the format accessible either, partly because the report starts with a great deal of detail on the process of the review and “methodology”. However the use of systematic research in this way produces weighty collective evidence and it is clearly a thorough, transparent and rigorous synthesis of the subject:

‘The synthesis shows that, while health staff may know about the physical effects of illness and its likely impact upon daily life, they know much less about what this means for older people and their life plans. Older people know about their own life plan, and what they fear might be the impact of the illness, but need carefully delivered information, and carefully delivered opportunities, to review their life plan in the light of their illness and to make their own plans accordingly. They also need the recognition that discharge might involve far more important issues (to them) than safety per se, and far more than being expected to accept passively any limitations consequent on illness. The synthesis shows that, in older people’s eyes, coming to terms was not a passive process of acceptance but an active working out how to manage, and how to preserve control over the most important things while accepting what must be given up’ (SCIE, 2006: 48).

This paragraph highlights some of the needs of older people leaving hospital particularly in terms of information and assistance with life planning.

Although its absence was not highlighted by SCIE, attention has been drawn in the past to the ‘comparative’ lack of social work literature on hospital discharge (Marks, 1994; Taraborrelli 1998). The former author also called for multi-disciplinary research, so that findings might be more acceptable to all relevant professions. Since 1998 the call does appear to have been answered to some extent, as discussed below.

3.2.2 Some landmark studies

It would also be interesting to chart improvements and the effect of research as well as policy upon practice over the years, although apart from some repeat studies (e.g. Waters 1987 and 2001) it is not possible to compare 'like with like'. Starting with Skeet's work (Skeet, 1974) undertaken soon after the establishment of social work departments in local authorities, older people left hospital with little support apart from their own families and neighbours. It is clear that post-discharge services at least have largely improved, even though there may not have been similar progress regarding health and social care working seamlessly together (Victor et al, 2000; Jewell, 1993; Tarraborrelli, 1998; Pethybridge, 2004). One of Skeet's 16 'urgent' recommendations to improve hospital discharge could after all be reiterated in 2009:

'..the deployment of medical social workers, district nurse and health visitors in group practices to make home assessments, to give total care to patients and to provide support, encouragement and advice for each other' (Skeet, 1974:8).

A comprehensive, influential study of discharge for older people, using qualitative and quantitative methods was that carried out by Neill and Williams on the 'eve' of community care's introduction (Neill and Williams, 1992). The report, which was referred to in the last chapter, covers processes, outcomes, and domiciliary input and includes the changing role of social work. They list a criteria for a 'good' discharge procedure, which does in comparison with more recent publications, appear a modest or an understated basic checklist, serving as a useful benchmark: 'that the elderly person:

- Is given at least 24 hours notice of discharge
- Is given an opportunity to discuss how they would manage after discharge
- Has somebody with them on the journey home
- Has somebody waiting for them at home
- Has somebody who calls to see them on the day of discharge.' (Neill and Williams, 1992: 82)

Only one in three of the Neill and William's sample of older people reported that they had experienced a 'good' discharge, in terms of their criteria. The study

findings were then used as a basis for working together to improve the process and practice, via a series of multidisciplinary seminars (Phillipson and Williams, 1995).

3.2.3 Government departmental reports

In the previous chapter the concept of hospital discharge was traced as one growing in centrality for policy makers from the Griffiths Report and NHS and Community Care Act 1990 (Great Britain, 1990. *op.cit.*), Modernising Social Services, 1998 (DH, 1998) and the Older People's NSF of 2001 (DH, 2001). These all specified more effective co-ordination between health and social care to achieve timely discharges for older people. In the above NSF, Standard 4 covered 'General Hospital Care' and it can be argued did reflect a concern for older people left on hospital wards for unnecessarily long periods (DH, 2001). The NHS Plan, 2000 (DH, 2000a) and the National Beds Enquiry 2000 (DH, 2000b) singled out delayed discharges for action, which eventually came in the form of the Community Care Delayed Discharges Act 2003 (Great Britain, 2003. *op.cit.*) as covered in chapter 2.3. Throughout the period there have also been Social Service Inspectorate (prior to the founding of CSCI, latterly the Care Quality Commission) investigations. It is not possible to examine all the material that has emerged from government departments. Instead I have tried to select the most relevant and interesting for the purposes of this study.

Starting with the 1993 'Social Services for Hospital Patients' reports (SSI, 1993): the outcome of an inspection of five local authorities from 1991-2, which was conducted to address the absence of reporting on hospital social work hitherto. Although the focus was neither upon older people or discharge itself, the third volume was devoted to the 'user and carer perspective' showing how awareness of this pre-dated the requirements of the 1990 Act. In fact the report was very positive particularly about social work contribution to patient well-being and there were quotes to illustrate the findings such as:

'They do provide a wonderful service – being in hospital is stressful enough without having extra problems. You need someone who is apart to help you see the wood from the trees' (SSI, 1993: 23).

The latter point could also be employed as an interesting argument against the merger of health and social work agencies, indicating that service users do not necessarily want or benefit from seamless, joint working with health and social care acting as a unified whole. Hospital patients may welcome the chance to talk to an

'outsider' or someone like the hospital chaplain, who is outside their own family and apart from the hospital system. In their evaluation the inspectors also state: 'Although the emphasis was on practical tasks rather than emotional support, users and carers commented on the caring nature of individual workers' (SSI, 1993: 23).

The three SSI reports evaluating social services for hospital discharge post community care were as follows:

- 'Moving On' (SSI, 1995a)
- 'Moving On – A Further Year' (SSI, 1995b)
- 'Getting Better? Inspection of hospital discharge' (Horne, 1998).

These three were different in structure and tenor from their earlier counterparts. Comments on the nature of social work skills were replaced by measurement of performance against initially eight standards, nine for the third inspection. All were examining care management and discharge only but while 'user and carer involvement and satisfaction' formed one standard to be met, the inspectorate started taking more of a systems approach to discharge arrangements:

'to be undertaken in a way that managed the tension between ensuring that there was a comprehensive assessment of patients needs and avoiding the potential impact on hospital resources of unnecessary delays' (SSI, 1995a:1).

At this time there was also concern for health and social care working closer together and 'Moving On' prophetically cited discharge arrangements as a 'litmus test' for effective joint working (SSI, 1995a: 1). The upheaval caused by the new community care arrangements were acknowledged and they found 'good effort' on the part of most of the local authorities as in working with health, setting up of new procedures, assessment and care planning. Moreover the eight users and carers whose journey they followed expressed satisfaction with the services. The social work role is not developed in any depth in the report, as in the previous one. Nevertheless 'Moving On – a Further Year' (SSI, 1995b) does refer to the tensions introduced by care management:

'Hospital social workers sometimes felt that because of the volume of assessment activity the social worker's role in elements of counselling and support for patients was being lost' (SS, 1995b:8).

In other words, resource shortfall was curtailing the use of social work skills within care management and this shortfall is mentioned in the publication as something to address in future planning of services.

In: 'Getting Better? Inspection of Hospital Discharge' (Horne, 1998), signs of resource strain were verbalised to the inspectors: 'staff across SSDs expressed concern... that pressure of work could drive them to become little more than a placement service' and the author cautions against 'any drift back towards service led assessments' (Horne, 1998: 5). Staff shortage also seemed to have the effect of delaying assessments and potentially increasing 'risk' for those with less complex needs who were sometimes not seen until after discharge. The pressures to release beds or 'intense pressure' even, impacting upon carers and sometimes causing assessment of older people's needs before they had fully recovered were further related issues.

As will be shown later in the chapter, these reports reflect the changing role of the hospital social worker, operating in the main as a care manager from 1993. It could be argued that there was little choice but to practice in more efficient ways given the increase in numbers of adults needing to be assessed, without a corresponding enlargement in the workforce and supportive resources (Payne et al 2002; Atwal, 2002; Davies and Connolly, 1995; Godfrey and Moore, 1996).

The Department of Health's prescription for good practice in hospital discharge arrangements came in the form of 'The Discharge Workbook' (DH, 2003a), updated by the Change Agent Team following the introduction of the 2003 delayed discharge legislation (Great Britain, 2003. *op.cit.*). The Workbook begins by taking a rounded approach to the problems that may occur leaving hospital, that is not just delays or poorly managed discharges but those that occur too soon and to 'unsafe environments'. The causes of difficulties in arrangements for people leaving hospital are attributed to a variety of issues including 'internal hospital factors', patient/carer 'involvement or choice', co-ordination and lack of resources. A 'lack of involvement of independent sector providers' in both operation and planning was also cited (DH, 2003a: 2). However since both provider organisations commissioned and the staff employed can change frequently, their involvement may not be as simple as it sounds.

The workbook has a whole chapter devoted to the involvement of patients and carers and has handy assessment checklists for the latter, clear standards for both and a discharge checklist for staff to follow. DH guidance has for some time emphasised the requirement for staff to plan discharge prior to or from admission. It is therefore unclear how all patients and their families can be fully engaged in the process from the start, particularly when people are very sick. From a social work perspective while 'social issues' feature in the Discharge Workbook's introduction and acknowledgment is made of the differing needs of users and carers, and attitudes to coping with illness, little attention is paid to social factors elsewhere in the manual, claiming or reinstating welfare benefits for example. Perhaps a more surprising omission is the effect of ill health upon decision making for the individual and the family affected.

Much of the book draws on the experience of health practitioners, using identified best practices including a contribution from the hospital where this study is based.

3.3 Themes from the literature relevant to the study

3.3.1 Post reimbursement literature

Prior to the introduction of fines for delayed discharges as outlined in the previous chapter, there was considerable disquiet particularly among health and social care organisations, commentators and academics about the consequences of the legislation and particularly about the ability for older people to be able to make unrushed life changing choices before discharge (Glasby, 2003; Rowland and Pollock, 2005). Rowland and Pollock point to a reduction in the number of acute beds and the paradox that this is curtailing choice for older people, or putting them under pressure to make hasty decisions at a time when 'choice' is being promoted by the DH. Critics included the House of Commons Health Committee concerned also that it would work against the aim of closer health and social care integration (House of Commons Health Committee, 2002).

The Counsel and Care organisation (C&C) while not carrying out formal research on the post reimbursement situation reported on the experiences of their members:

'C&C has witnessed a change in the culture of hospital discharge since the introduction of the Community Care [Delayed Discharges] Act 2003 The McC family were under pressure from the hospital to get their grandmother

to move on but neither she nor they had been involved in any discharge plans' (Counsel and Care, 2005:11)

Since the Act came fully into force the CSCI reports (CSCI, 2004a and 2005) of national investigations of seven local authorities were the first pieces of published research found on the legislation's effects upon discharge of older patients. In fact the CSCI team spoke to managers, rather than practitioners and did not cover older people's involvement in the process apart from general discussions around promoting independence and direct payments. 'Leaving Hospital – revisited' (CSCI, 2005) concludes that developments in partnership working, the use of intermediate care and rehabilitation and the spending of reimbursement funding were encouraging in the majority of the localities they looked at. In the first year of implementation others were similarly positive about the impressions they had of the way health and social care were working with reimbursement to the point where it had unexpectedly brought the two sides of the 'Berlin wall' closer together (Henwood, 2004; Hudson, 2004; Lymbery and Millward, 2004). However CSCI remained concerned about widespread 'fragilities' in home care provision, the continued rise of emergency admissions, and, as discussed above the pressure on older people to make quick decisions on a move to a care home (CSCI, 2005).

In his text book 'Social Work with Older People' Mark Lymbery describes what he sees has been the effect upon social work practitioners working in hospitals post reimbursement. He wrote that the latter:

'has led to a particular emphasis on the role of hospital social worker in enabling the more cost effective use of hospital resources, which has served to limit their wider involvement in treatment or rehabilitation even further' (Lymbery, 2005 : 176).

The 2006 Review of progress against the *National Services Framework for Older People* (CSCI, CHAI, and NAO 2006) draws upon the work of the CSCI over 2 years [already discussed above] and some new inspections for their consideration of 'Hospital discharges and readmissions'. The authors comment that:

'Although delays had fallen in all inspected communities, in some cases rapid discharge was only achieved at the expense of proper planning with the older person concerned' (CSCI, CHI and NAO 2006: 42).

They go on to report satisfaction rates of 63% - 81% but, note that a 'significant minority' were unhappy with their discharge which was also 'sometimes done at

inappropriate times' for older people and their carers. Furthermore the team looked at re-admission rates for those with some chronic illnesses and found an increase in these rates for both diabetes and chronic obstructive pulmonary disease sufferers for those aged over 75.

Following the introduction of reimbursement in 2003 the DH commissioned large-scale multiple-site research on the effects of the delayed discharges legislation. One study evaluated comparative evidence from hospitals in England and Scotland where although strategies were adopted to tackle delays in discharge, these were set at reducing those over six weeks as opposed to the English stipulation that a discharge was deemed 'delayed' after three days (Hubbard et al, 2008). Furthermore while extra funding for community resources were made available in both countries, no system of fines for LAs was introduced in Scotland. The other study looked at six English hospitals that had achieved low rates of delayed discharges to find what could be learned from their experiences to benefit other sites (Baumann et al, 2008). The findings from both studies together with the earlier literature review referred to above (Glasby Littlechild and Pryce, 2003) were synthesised in an overview of research supporting the review of the 2001 NSF for Older People (Askham, 2008). Drawing on the research projects conclusions, the latter overview states that reimbursement as a policy 'has run its course' and that one of its consequences was 'social work could suffer from blame' (Askham, 08: 5). While evidence from one study supports those assertions (Hubbard et al, 2008) that from the other study found that reimbursement had led to more positive joint working (Baumann et al, 2008). The latter authors wrote about health and social care professionals' uniting around the organisation of new systems and designing/operating joint protocols. Moreover the issuing of Section 2 notices of readiness for discharge was said to be helpful to social workers and the process makes clear where the responsibility for any delay to discharge lies (Baumann et al, 2008). It is acknowledged by this research team however that joint working was already advanced and delays to discharges were low in the hospitals studied. More importantly for older people although they welcomed being able to leave hospital as soon as possible; it was concluded that personalisation of care, adequate time for decision-making, and continuity of care from social workers have been sacrificed (Askham, 2008). In their summary report Hubbard et al usefully encapsulate the complexity of decision-making and therefore something of the difficulty in achieving a person centred experience:

‘What is evident in many patients’ stories is that decision making on discharge is affected by an interplay of factors – personal preferences, needs and desires of users and carers that may also conflict, and different professional perceptions about how best to meet needs. These were played out in the context of system pressures, service capacity and discharge processes’ (Hubbard et al, 2008:4).

To comment on the structure of these studies briefly, one project’s researchers interviewed older people delayed in hospitals, together with informal carers and the professionals involved (Hubbard et al, 2008). Consequently those older patients who had passed through speedily and had gone to transitional units or care homes were not interviewed about their discharge. It is therefore possible that older people who were not delayed in hospital, particularly those with complex needs, may have had more rushed experiences of assessment and care planning. The other research project in the group however spoke only to health and social service professionals (Baumann et al, 2008), but social workers were included and not just their managers as in previous similar studies (CSCI, 2004 and 2005). The authors comment that for nurses, discharge of patients is just part of their role while it is a ‘key role’ for all the other groups interviewed including care managers (Baumann et al, 2008:107). The conundrum here then is, whether that was usually the case or perhaps meeting reimbursement targets has meant that most care managers are now focused mainly on arranging hospital discharges. It will be interesting to see if a clear picture emerges of how proportions of workloads are distributed for care managers in my study hospital.

3.3.2 Involvement/participation of older people

Older peoples’ experiences of involvement and participation in planning of services are of major concern but before looking at the theme, it is perhaps useful to consider involvement and participation as concepts. There is a considerable amount of literature on this topic, (Roberts, 2001) and in particular attempting to define what is meant by the terms, often used interchangeably or on a continuum from consultation to empowerment. Many authors invoke Arnstein’s ‘ladder’ of citizen engagement (Arnstein, 1969) in relation to this continuum. Here she suggested eight stages of engagement with manipulation at the bottom or ‘non-participation’ end, through to informing, consultation and placation as degrees of tokenism at the mid-way point, to the top end of partnership, followed by delegated power and citizen power at the ladder’s apex, as degrees of citizen power. Titter and McCallum have since critiqued the model in relation to user involvement in health provision. They argue that Arnstein’s linear approach is focused on outcomes rather

than processes and that it does not take account of different types of knowledge for example. They propose a 'more nuanced model' in the form of a mosaic of multiple ladders with bridges between. (Tritter and McCallum, 2006:166).

With regard to social workers involving older people in decisions on the provision of services, the NHSCC act of 1990 makes explicit the central role of the user and user choice, which has always been problematic for practitioners to reconcile with limited budgets (Allen, Hogg and Peace, 1992). Ten years after the publication of 'needs led and consumer focused' reforms Richards argued that there was 'little evidence' of change to social care practice. She saw this being due to both a lack of adequate funds and 'ambiguities and tensions inherent in the reforms' (Richards, 2000:38). The last chapter also referred to the legacy of community care reforms and targeted social care.

The contested nature of concepts such as 'participation' and 'empowerment' has been explored (e.g. Harding and Beresford, 1996; Braye and Preston-Shoot, 1995). In the opinion of the latter author participation has become an end in itself, as well as the means to an end. That is not to say that this is necessarily a negative interpretation, for the very old or sick, participation to achieve long-term goals may be unrealistic. Some commentators and academics have also sought to distinguish between 'empowerment' and 'involvement', as defined by governments to mean 'consumerism' since the marketisation of social care was imposed in the 1990's (Barnes and Walker, 1996). The approach implies that the service user is able to freely choose services from a range available and has the power to change/withdraw from such arrangements at will. Beresford and Postle have linked a governmental consumerist model of involvement with managerialism and have contrasted that with movements of social democracy. Furthermore in an updating of their argument they conclude:

'As with direct payments, resource constraints and lack of real choices mean that that individual needs may remain unmet and a passive relationship between service user and provider is perpetuated' (Postle and Beresford, 2006:232).

In the arena of social care, empowerment is discussed as necessarily implying the transfer of power from the agent, the social worker for instance at the micro level or local authority at the macro, to the service user or their chosen representative organisations respectively (Wilson, 1995; Hobman et al, 1994; Clark and Spofford,

2001). In practice terms some of the earlier writing on the subject referred to the pivotal role of the user who should be their own care manager unless there is a very good reason not to be (Smale et al, 1993; Ellis, 1993). Later, although this idea may not have become a reality for various reasons particularly in hospital settings, there is at least the view that the user should be a member of the multi-disciplinary team (Roberts, 2001). The extent to which the latter has been adopted is looked at in the literature of the next section.

Not only has defining and finding participation and empowerment been a common issue in the literature, but also the measurement of the extent of involvement of users in care management processes (Marsh and Fisher, 1992; Wilson, 1995). Marsh and Fisher's research has shown that token involvement was common with little reference to the latter in social services records. While not denying findings such as these, others have argued that a contributory factor was the overwhelming feeling of powerlessness felt by social workers and care managers themselves (Stevenson and Parsloe, 1993). This factor is echoed in later findings on the ability of the care manager to advocate on behalf of patients in the inter-professional arena of the hospital (Bradley and Manthorpe, 2000; Stanley, Reed and Brown, 1999).

Looking at work specifically on carers' issues re hospital discharge, Carers UK have published a survey disseminating the results of 1,409 questionnaires returned by carers on the subject (Hill and Macgregor, 2001). Only one in four respondents were given a choice about whether or not to undertake the caring role. Furthermore 36% said that they had not been consulted on discharge plans and 9 out of 10 patients were felt by carers to have been sent home too early.

Older People's Participation in the Discharge Process

Most investigators since 1993 have noted an absence of participation in discharge planning for older inpatients (Victor et al 2000; Tierney 1994; Godfrey and Moore 1996, Bull and Roberts, 2001, SCIE, 2006). Two studies also pointed out that there was little evidence to support the claims made by hospital trusts that older people and their carers were fully involved in discharge arrangements (NAO 2003, Pethybridge, 2004).

The reluctance of some older people to participate in discharge planning when this has been offered to them, preferring the professionals to take decisions for them, (Roberts, 2001) is not altogether surprising and can be said to relate to low self

esteem, and deference to experts (Wilson, 1995). This tendency was also discussed by Myers and MacDonald (1995:91) who looked at staff, users and carers' experiences of care management. They concluded, 'the ceding of power may itself be a positive choice' and refer to Stevenson and Parsloe's work (1993) in arguing that:

'the concept of empowerment needs to be specifically related to the different material needs of very elderly people, and may need to encompass the older person seeking to hand over tasks which worry them' (Myers and MacDonald, 1995:91).

The authors then cited Robertson (1993) who suggested that older people 'sought' a care manager with status, expertise and advocacy skills to act on their behalf but bearing in mind, they point out, that care managers themselves have to allocate 'scarce resources' and have their own 'other agendas' (Ellis, 1993: 39). These might include identification with agency and professional priorities such as meeting performance targets and safeguarding obligations. As discussed in the previous chapter, with the growth of Internet use and consumer power it will be interesting to see how attitudes of tomorrow's older people change. Results from another study (Littlechild and Glasby, 2000) showed a high level of motivation among older people to participate, although the authors noted that tendency among respondents to internalise negative media images such as 'bed blocking'. This apparently affected the research participants to the extent that older people were unwilling to seek medical help initially, and to take up the doctor's 'valuable time'.

Huby et al conducted a study looking at the interesting angle of older people's participation in discharge planning and the link with 'risk management' (Huby et al, 2004) using observation and interviews with 22 participants. They found older people passing decision-making on to their carers or 'younger family members', deference to doctors, absence of older patients from multi disciplinary assessment meetings and a failure to deal with social and psychological factors that would have a bearing on post discharge coping mechanisms:

'The focus narrowed to particular physical or cognitive functions, interpreted out of the context of patients' management of their lives' (Huby et al, 2004:130).

By illustrating their findings with two case studies and quoting passages from their interviews the authors portray a convincing and rounded picture to support their

conclusions. The methodological implications of assertions made in the conclusion of their paper are looked at below in 3.4.

More recently Huby et al have published a second paper, an ethnographic study on the role of 'interprofessional practice and older patients' participation in decision-making about discharge' (Huby et al, 2007). Observations and Interviews with 22 patients produced interesting findings on independence and decision-making. In particular the ability of older people to adjust to their new situation, often one of disability was not used as a '*resource* in decision making ' with assessment that reduced patients to their functional elements, and prevented negotiation or engagement. Moreover the authors comment that older people found themselves struggling 'to relate to a system of professionals' (Huby et al, 2007:64). Importantly they concluded that interaction not labelled as decision-making processes could nevertheless trigger significant action. Like others Huby et al indicate the complexity of decision-making (e.g. Hubbard et al, 2008) in discharge planning.

Examining the depth of consultation more closely, variation depending on former occupation or social class has been suggested (Roberts, 2002; Davies and Connelly, 1995). Linked to this is the position of the sensory impaired and those from minority ethnic groups, who it is argued are in particular need of advocates in the hospital setting (Henwood and Wistow, 1994). Karen Roberts's study of older people accessing community support post discharge discovered that: '22 out of 30 reported having been consulted or at least spoken with about their perceived needs and service requirements on discharge from hospital' (Roberts, 2002:416). She further commented that, her data showed that older people were more willing to accept health rather than social care at home. She does not indicate whether this might be due to the effect of means testing and charging for services, as well as other factors described such as ease of access and "doing what your doctor tells you".

3.3.3 The contribution of social work to the discharge process

Pethybridge's study focussing on team working in discharge planning refers to social work in that context, (Pethybridge, 2004) but found that it was the ward sister who tended to co-ordinate discharges. Apart from this paper, there appears to be little published literature either written from a social care perspective or looking at social work/care management's contribution to hospital discharge. Exceptions include work such as McLeod's et al (2008). Most general social work texts seem

not to refer to hospital work specifically although Mark Lymbery's paper below discusses care management in an interprofessional setting, with particular reference to health agents (Lymbery, 2006).

The Department of Health/ SSI reports outlined in the section above were the last government departmental reviews of hospital social work and they present a flavour of the translation of policy intentions into practice. Following a study of hospital social work in Scotland, which gave a positive endorsement of its contribution to older patients and their effective discharge planning (Connor and Tibbitt, 1988), the Inspection of 1993 (SSI 1993) was equally encouraging. From the users' perspective it referred to skills of 'listening' and characteristics such as showing a 'caring nature' through direct quotations from respondents. In 1998 care management procedures were evaluated without a mention of such long held basic social work skills regarding the relationship with service users and carers and knowledge sharing. These seemed to have been replaced with terms such as 'monitoring information' and performance measures (Horne, 1998). From a similar time period studies were published that found improvements in both service outcomes and the standard of social work assessment of older peoples needs, such as Healy, Sergeant and Victor's work (1999). However they searched client records rather than ascertain service users' views directly. Furthermore whilst there was evidence of collaboration between agencies and 'strenuous efforts' to this effect, Healy et al reported that services tended to be profession/service led rather than by needs/user driven.

Historically the role of the hospital social worker has been examined at intervals since the metamorphosis from 'almoner' in the early 1970's as described in the previous chapter. Law's research project was one of the first published, a rounded view of a social services department's work in the whole hospital and while one third of clients were over 60 in 1976, their discharge or it's planning is not mentioned (Law, 1982). Interestingly, scrutiny of the casework undertaken by social workers at the time revealed that 42% of cases involved 'emotional' or therapeutic intervention and was by far the biggest category of six groupings that included financial and general advice. That is not to suggest social workers then had plenty of disposable time, as pressure of referrals was apparently constant.

Twenty years later, following the introduction of care management and the community care reforms, studies found hospital social workers reporting that they

had no opportunity for preventative work, let alone for any counselling (Davies and Connolly, 1995; Bradley and Manthorpe, 2000). The picture of care management changing the social worker into a 'box-ticking' or 'pen-pushing' bureaucrat was painted by Rachman (1995) and confirmed in a more recent exploration (Pethybridge, 2004). Phillips and Waterson (2002:180) in their paper on social work and hospital discharge, sum up the changes to the role during the 1990's in describing lack of support to carers:

'Prior to 1990 such emotional support would have been seen as a core task, whether it was provided or not. Care management has rendered it invisible or serendipitous'.

Lymbery succinctly summarised the 'threats' he perceived to social work with older people in general (Lymbery, 2006), but the following points are all relevant to the hospital context as he was looking at multidisciplinary, interprofessional contexts:

- '1. The power of other occupations within health and social care – notably medicine- to define and control the nature of social work practice.
2. The potential pressure of other occupations that occupy a broadly similar position to social work – e.g. nursing and occupational therapy – to claim aspects that are legitimately part of the social worker's role as belonging to them.
3. The ability of managers to define the work of a social worker so narrowly that it could be claimed that a professional social work qualification is no longer required.' (Lymbery, 2006: 1131)

Lymbery makes the case however that social workers have a special contribution to bring to inter-professional working with older people: their anti-oppressive and holistic values or perspectives, relationship forming abilities, co-ordination skills and totality of collectivist, therapeutic and administrative approaches. The doubt remains nevertheless as to whether any of these aspects are possible within current social work practice with the majority of older people in hospital.

The dilemma of 'throughput' of older people versus 'individuality' and quality care management has been present from the 1990's onwards judging by the many vivid accounts given by older people and their carers in papers published at the time (e.g. Henwood and Wistow, 1994; Phillipson and Williams, 1995). Nevertheless a later qualitative evaluation of older people's opinions of social work in an accident and emergency department (A&E) concluded that although a social worker may not

prevent hospital admission - the NHS Trust's original rationale for their presence - older people had much to gain from social work intervention (McLeod and Bywaters, 2003):

‘ It helps them to negotiate the unfamiliar A&E environment, to be better informed about issues crucial to managing their own health, to receive more support with the emotional rigours of attending A&E, and assists with the complexities of planning future care’ (McLeod and Bywaters, 2003:799)

The researchers conducted 28 semi-structured interviews with older people two to three weeks after attending the A&E department. The same authors in their book *Social Work, Health and Equality* (McLeod and Bywaters, 2000) discuss the difficulties of some older people in accessing a social worker in hospital. As in other literature (e.g. SCIE, 2006), they further stress the value of follow up for these patients.

Another theme from the literature is the role of social worker as an advocate for patients' rights, in a multi-disciplinary setting of the acute hospital. In the discharge process this has been around negotiating with doctors/consultants on behalf of the older person for more time in hospital usually to allow for placement of choice to be vacant, or for carer to prepare at home (Neill and Williams, 1992; Davies and Connolly, 1995). It has also been noted that a social worker/care manager battling on her own in a multi-agency meeting, for example, can end up more as a 'go-between' (Bradley and Manthorpe, 2000; Stanley, Reed and Brown, 1999) such is the hierarchical nature of hospital professional relationships.

In a more recent study of social rehabilitation McLeod and colleagues have written about the importance of social networks to older people following discharge and the social care role in accessing those networks (McLeod et al, 2008). Although their work was an evaluation of voluntary sector discharge teams, they raise some significant points that are relevant to my study. They highlight the significance for service users of both the relationship with social care workers and how 'processes' are carried out. Importantly they called for a holistic, 'comprehensive' approach of workers performing an 'educative and advocacy' role alongside 'interpersonal interaction' recognising 'interdependence', that older people prefer to *continue to be* 'givers' as well as receivers. They demonstrate the shortcomings of a six-week period of intermediate care, which has been the period of entitlement to services

during rehabilitation. The 'essential preliminaries' that older people need to have to enable access to social networks (McLeod et al, 2008:87) are in the authors view:

- 'Older service users should not be discharged from hospital when too ill to cope; the Department of Health's own figures on older service users' emergency re-admission within a month of discharge indicate that this is false economy, setting aside the psychological and physical distress that may be needlessly induced;
- health and social care services need to be sufficiently well funded and coordinated at the point of discharge, to ensure that the transition to home is not a health-damaging experience;
- in the interests of sustaining both short and longer-term health and wellbeing, assistance with 'low-level' personal care, where necessary, needs to be integrated into 'intensive' intermediate care on an extended basis;
- equalizing access to services remains a key priority.' (McLeod et al, 2008:87)

Tying in with the second point above continual staffing shortages and the ever shrinking time scale for assessment for discharge, for the actual planning process itself and to get to know the older patients on the ward, have been evidenced by many investigators (Victor et al 2000; Tierney, 1994; Davies and Connolly, 1995; Godfrey and Moore 1996; Atwal, 2002; Payne et al 2002). Margaret Gregory portrays the effect on all stakeholders graphically in her thesis written prior to the introduction of the *added* effects of reimbursement:

'The amount of stress generated because of the double dilemma, lack of resources and shortage of time was on occasions almost unbearable for the carers and hospital social worker, i.e. lack of vacancies in care institutions coupled with no time to make arrangements because of the need to discharge quickly, this resulted in many patients in the study going to live with a carer' (Gregory, 1997:175).

Atwal's research (2002) also contains revealing observation of nursing staff 'dreading' the appearance of the care manager on the ward because of being so busy whilst also having to continually chase up care managers to visit patients and for their assessments etc. (Atwal, 2002).

Finally, some research data from interviews with older service users leaving hospital have shown that not only were they unaware of a social work/care assessment taking place (Godfrey and Moore 1996) but also of the role and job being performed by the care manager (Tulle Winton, 1995; Stanley, Reed and Brown, 1999). These findings have been confirmed by later research, which also uncovered confusion with other professionals and titles such as occupational therapist (Manthorpe et al, 2008).

3.4 Methodological issues

It is apparent that a number of nursing studies and probably the majority of social work research identified in this area do not make the methodology explicit, although there may be reference to underlying philosophy or to the standpoint taken. Some particularly interesting examples of work from a phenomenological approach, deploying interpretive methods have been found however. These are mainly in the nursing field, and describe in detail the experience of illness and lifestyle changes for older people (Higgins, 1998; Nay, 1995; Kellett, 1999; Madjar and Walton, 1999). The debate about practitioner or professional knowledge and its relationship to research (as discussed by Schon, for example) is relevant here, (Schon, 1991). Moreover the knowledge base for social work it has been argued is a 'continuing interactive process' (Payne, 2001).

To summarise, the majority of studies tend to either use quantitative survey methods with large representative samples, (e.g. Lester and Jones, 1994) or small localised in depth qualitative interviewing (e.g. Stanley, Reed and Brown, 1999) and occasionally a mix of both (e.g. Neill and Williams, 1992). With the exception of the CSCI studies (CSCI 2005, 2004a) and more recent large-scale research for the NSFOP review (Baumann et al, 2008; Hubbard et al, 2008) the qualitative studies of older people's experiences in this field do not on the whole claim to offer representative sampling with a portrayal of discharge experiences that can be applied to the whole country. Yet quantitative research, which consistently finds older people very satisfied with the NHS, may not adequately reflect the views of older respondents, it has been argued (Manthorpe et al, 2008; Carr-Hill, 1995).

In an article considering the duty of local authorities to measure satisfaction of community care recipients, Chesterman et al aimed to 'unpick' the complexity of adopting satisfaction ratings (Chesterman, Bauld and Judge, 2001). For the purposes of this review, interesting findings were that users were more satisfied

with services set up by qualified social workers and the more time spent on this the higher the satisfaction. Ratings also varied with location of residence and they discovered that areas with lower charges for services coincided with higher satisfaction levels. 'Life satisfaction' and personal well-being were found to affect opinion of provision making it difficult to accurately draw conclusions from survey data. Positive effects of services can influence users views of outcomes just as problems such as isolation and keeping warm:

'Expressions of satisfaction can be related to seemingly 'objective' aspects of services but they are also a function of user and carer circumstance and characteristics that have little or nothing to do with the receipt of services' (Chesterman, Bauld and Judge, 2001: 41).

Huby et al's work which looked at the link with older people's participation in the discharge process and risk management (Huby et al, 2004) was referred to above. By illustrating their findings with two case studies and quoting passages from their interviews the authors portray a convincing and rounded picture to support their conclusions. They argue in the end however that 'like assessments interviews alone produce a one dimensional view of patients experience of their hospital admission' and they call for methods which 'in a variety of contexts capture the complexities of competence' (Huby et al, 2004:131). While their study may have shown this to be valid, they carried out all their interviews within the hospital, and the institution itself as they acknowledge may influence behaviour.

Bearing the latter caveat in mind regarding analysis of data generated in my study, a review of the research which reports on interviews with service users is convincing that this was an appropriate way to proceed, especially as there seems to be no substitute for service users speaking for themselves, their direct experiences bringing life to the text. Quantitative approaches with a method such as a large-scale survey using random sampling might be a quicker way of reaching larger number of representative participants across more than one site. It could then be possible to make greater claims for the wide applicability of the research findings. Nevertheless as discussed above, older people, particularly those discharged from hospital might find a survey too difficult or troublesome to respond to for a variety of reasons. Even if they are able and willing to complete a questionnaire, they may not wish to give much detail of their experiences including their emotions on paper. These are what my study seeks to capture. Manthorpe et

al (2008: 1135) summed up the situation regarding choice of methods for eliciting opinions of older people:

‘satisfaction surveys may generate poor-quality or puzzling data (Quereshi, 2002; Quereshi and Rowlands, 2004), and, in interview many older people appear to be cautious of appearing critical of services or the staff who provide them (Chesterman et al., 2001; Ware et al., 2003). To counter some of these problems we adopted a rapid appraisal approach (Ryan et al., 2001)...’

The following chapter describes some of the pitfalls that qualitative research interviewing can encounter, demonstrating that this is neither a quick or easy option with outcomes that are often not clear-cut but nevertheless interesting and illuminating.

3.5 Conclusion

Studies show continued difficulties experienced by older people leaving hospital in terms of lack of participation in their plans, lack of choice of alternatives post discharge together with limited support and information for relatives particularly of older people with more complex needs. In my study I set out to gain a sense of how issues such as these impacted upon individuals. Throughout, as looked at in the previous chapter, the background to my research project is one of limited resources for social care influencing staff time, availability of care home places and other provision. The literature has shown the effect of change from social work to care management and an increased role for discharge planning at a time when people are leaving hospital quicker than before. All this has reportedly caused additional strain upon practitioners in hospitals.

Until recently (e.g. Hubbard et al, 2008) there has been a surprising lack of acknowledgement in the literature of anxiety for older people leaving hospital even for those moving to a new location afterwards. Furthermore research still seems to often focus on older people who are delayed in hospital (e.g. Swinkels and Mitchell, 2008) but the experiences of those who have a swift discharge to home or elsewhere appear to be given comparatively less attention. Perhaps this is partly due to the difficulties in tracking prospective study participants post discharge.

To summarise the following are substantive issues found in the literature of older people’s experiences of leaving hospital and the role of social workers in the process, and therefore those most relevant to my research topic:

1. The success of reimbursement as a policy

From a social care perspective the benefits of the introduction of the policy remain uncertain. There is broad agreement that pure numbers of delays to hospital discharge of older people have reduced and that the policy has at least exposed the reasons for such delays that still occur (Henwood, 2006). There is some suggestion that delayed discharges have risen again (Krishantha et al, 2009) and that waiting has shifted location as older people are often moved on to transitional or 'holding' units in certain areas (Hubbard et al, 2008). It was therefore of importance to me to try to discover what was happening to service users leaving the study hospital and their experience of the impact of reimbursement if any upon their discharge. The latest large scale research has led to a call for the ending of the policy and for a refocus of attention away from entry and exit points (Askham, 2008). Whether more attention should be given to older people in the community, including those treated at home or in hospital was not entirely clear.

2. Joint working relationships.

Firstly, the effect of reimbursement upon health and social work acting together in hospital remains contested. Some writers claim that the policy has led to closer collaboration on local protocols (Baumann et al, 2008; CSCI, 2004), that a culture of blame upon social workers does not exist (Swinkels and Mitchell, 2008); but other research has pointed to the policy for causing a negative impact on relationships for that same reason (Hubbard et al, 2008).

Secondly, longstanding evidence of disharmony and tension between social care is recorded and discussed in the literature from health professions encroaching upon social work's territory, differences in approach and process to minor disagreements arising from stress of tight timescales and the pressure to discharge. In planning how to generate data for my study, knowledge of these tensions as portrayed in the literature leads me to consider carefully the most appropriate way to capture data and specifically in these circumstances whether inter-disciplinary focus groups might be inappropriate lest they are permeated by tensions as outlined above. This area is further explored in the next chapter on methodology.

3 Who co-ordinates discharges?

This question is specifically regarding older people with both health and social care needs leaving hospital. Having found that the literature either refers to the ward sister/key nurses or occupational therapist as co-ordinators (Pethybridge, 2004), recent research names the social worker in the most powerful position here (Swinkels and Mitchell, 2008). In a sense this debate, while of interest may not be significant to older patients who according to past research (e.g. Neill and Williams, 1992) want their discharge to be managed at the right time for them, with sensitivity to their individual health and social care needs. Nevertheless it is clearly important to be open minded about this and all other topics in seeking service user and carer perspectives on what matters to them. The literature however tells us that in arranging the discharge professionals' discussion with relatives and/or carers is vital as is continuity (Hubbard et al, 2008) and that someone is responsible for co-ordination, paying attention to transport, medication, aids and equipment, support services including meals; finances, contacts, follow-up and social networks post discharge (MacLeod et al, 2008).

4 Who is the care manager or social worker?

If the study had been conducted from a therapist's perspective, they could be asking a similar question of themselves (Manthorpe et al, 2008). The query from the patient's perspective is recorded in research and seems to apply even where an older person has undergone a full assessment by a social worker (Godfrey and Moore, 1996). As is noted, staff and volunteers in many different guises populate hospitals, wearing a variety of uniforms from the chaplain to the domestic. In moving onto collection of data for the research project, these are issues I needed to be mindful of in asking interview questions. The situation pertaining to social services is not helped by turnover of personnel and in that respect other professionals as well as users may not feel they know the social worker. Older patients and even social workers themselves have also expressed a lack of knowledge about the role of care manager in hospital discharge (Stanley, Reed and Brown, 1999).

5 Change from social worker to care manager.

Older people's views of the social work role per se can be 'unclear and variable' (Manthorpe et al, 2008:1133) although in the past social work services to older

people attending hospital A&E for example, were judged to be highly beneficial (MacLeod and Bywaters, 2003). A number of studies and commentaries in the review have major reservations about the effectiveness of care management as opposed to social work, both in the hospital and community settings (Phillips and Waterson, 2002; Rachman, 1995). It can be observed however that care management fits with a streamlined NHS and hospital discharges and market driven/privatised social care (Tanner and Harris, 2008). The management of a care package is seen as procedural and being concerned with tick box assessments providing at its unadorned extreme neither social caring or *social* work service to users and carers or job satisfaction to care managers themselves (Lymbery, 2005). The interesting issue here is how social workers cope and have adapted practice under these circumstances in the study hospital and more importantly how service users and carers cope as recipients or partners. Hence an aim of data generation will be to tease these issues out via conversational style interviewing.

6 User involvement and person centred care

The extent to which service users are involved in their discharge plans or want to be involved, and the permutations along that continuum in addition to the complexity of such decision making, are considered by many researchers (Hubbard et al; Huby et al, 2007; Roberts, 2001; Reed and Stanley, 2000) and will inform my study's data generation. The role of family and carers is important here, as well as risk for those with complex physical/mental health needs. Also identified in the literature are the difficulties professionals face in assessing patients - particularly those in the latter situation and with changing needs - in a person centred way in the current climate of rapid discharge (Hubbard et al, 2008).

The next chapter returns to study methodology and methods in more detail, which requires explanation and exploration before we can turn to data presentation, analysis of the data and discussion of the findings in Chapter 6 onwards.

4 Methodology

'No study conforms exactly to a standard methodology; each one calls for the researcher to bend the methodology to the peculiarities of the setting.' (Miles and Huberman, 1994: 5)

4.1 Introduction

In this chapter I examine the philosophical underpinning and following on from that the appropriate methodological approaches to the research topic, focusing on phenomenology as the guiding paradigm for the study. I then describe the method of and plan for data gathering between 2004-6, in order to achieve the aims of the research project in 1.3. To satisfy the first study aim of exploring how service users experienced the discharge process four illustrative case examples are constructed in the thesis to give a full picture of those experiences for individuals; the chapter will therefore consider the case study method and its application to the presentation of the case examples in the thesis. The validity of the research is looked at and finally there is a detailed account of the ethical considerations involved in conducting the study and how these were addressed. Actual methods used and the gathering of data is discussed in the next chapter, 5.3.

4.2 Study methodology

4.2.1 Guiding philosophical approach

Underlying philosophical foundations

Returning to the beginning, I started with a research problem as in 1.3, that I wished to explore, broadly speaking – how service users and their carers experienced hospital discharge and social work in that context. Before deciding on practicalities and the tools I might use to do this however, I needed to engage with ontological and epistemological debates, as Lincoln and Guba (1994:108) put it:

- What do I consider is the form and nature of reality **or** put simply 'what do we know'? – my ontological stance
- On that depends the answer to what is the relationship between the 'knower' and what can be known or 'how we know it' - the epistemological stance

In consideration, I would argue that the paradigm governing the study is one of subtle or critical realism i.e.: external reality exists independently of our beliefs but reality is only knowable through the human mind and socially constructed meanings (Snape and Spencer, 2003:11). My position therefore is that there objective realities do not exist as 'hard facts' that can be scientifically investigated or one derived from positivism. Qualitative researchers in general vary in their ontological/epistemological stances but "there is a common understanding that the social world is influenced by normative expectations and shared understandings" (Snape and Spencer, 2003:23).

From my stance follows a methodology that is interpretivist or phenomenological, as I go on to discuss below, recognising that the researcher and social world impact on each other and research findings are influenced by researcher's perspective and values. In general qualitative researchers argue that it is impossible to conduct objective, value free research of social phenomena. But the researcher can and ought to be transparent about her assumptions. This interpretivist methodology clearly has implications for the methods used in the study. Firstly, methods derived from natural science such as 'deduction' are not appropriate as the social world is not governed by unchanging regularities or laws but mediated through meaning and human agency (Snape and Spencer, 2003). Hence the researcher is concerned to explore and understand the social world using both study participants' and her own understanding. Secondly, induction as applied to my study looks for patterns and associations derived from perceptions of the social world -in this case through analysis of interview and focus group transcripts, rather than starting with hypotheses to test.

Many of the debates around positivist or interpretivist approaches and qualitative/quantitative methodologies or mixed methods have been conducted for centuries and are still going on. In the social world we can never find 'the answers' let alone agree on the questions to ask, or the kind of form those questions should take.

Discussion on the application of phenomenology

Given the ontological and epistemological positions described in the previous section, the methodological approach to the subject of this research that impressed immediately as having the best fit was that derived from the phenomenological philosophy of Husserl from circa 1911. Heidegger and many others have since

adapted the approach, but it seeks to reach and thereby describe the 'essence' of individual experience. Van Mannen identifies 6 orientations to phenomenology: transcendental, existential, hermeneutical, linguistical, ethical and experiential (Van Mannen, 2002). These orientations in themselves could be the subjects of whole theses. In brief, the hermeneutical tradition developed by Heidegger, Gadamer and others takes phenomenological inquiry beyond description to explore deeper meanings, in the interpretation of text conversation and language.

In the previous chapter I referred to the work of a number of nursing researchers (e.g. Caelli, 2001; Hallett, 1995; Higgins, 1998) who have successfully made sense of and adapted phenomenological methodology to guide studies on the way various illnesses, procedures and aspects of the nursing role are experienced. Its relevance for social work research may be seemingly plain but I have found little mention of it in the context of studies around social work/care or older people. However, in journal papers the chosen methodological approach seems rarely to be specified, beyond a reference to qualitative/quantitative or mixed methods, probably due to compliance with a limited number of words. On closer examination, one piece of research I had respected and wished to follow up referred to a 'broadly phenomenological overall approach' (Stanley, Reed and Brown, 1999:230), which was reassuring. Another piece of research that I wished to follow up defined itself as a 'case example' and the only mention of methodology was a 'qualitative approach' (Phillips and Waterson, 2002:171). Nevertheless, the first of the above studies encountered difficulties with participants lack of recall of their care manager so as I embarked upon gathering my data I was aware of this particular pitfall and did consider whether my service user participants would be able to remember their experiences and remember them in detail. Other concerns are voiced in section 4.3.1 on qualitative interviews.

Alternative commonly utilised qualitative methodologies of grounded theory and ethnography tend to concentrate upon generating theory and on examination of cultural values/beliefs respectively (Morse and Field, 1996). Pragmatically it also seemed clear that it would be difficult to immerse myself in the hospital setting and respond to the projects aims of finding out about service user's experience of discharge adequately as an ethnographer. Grounded theory's concern for 'objectivity as a research stance' (Patton, 2002: 129) did not fit with my own approach, which Poindexter expressed so eloquently as outlined below (Poindexter, 2003: 405-6). I will also be arguing in 4.5 why it was not feasible to use the case

study approach in its pure form, as access to a wide enough spectrum of sources to throw light upon 'a case' or cases was not possible. Instead illustrative case examples are used in the thesis to aid understanding of individual participants' experiences. Hence, whilst these alternative methodologies also share a great deal of common ground, phenomenology appears more appropriate for this study.

The value base of phenomenological methodology is important moreover for its adherence to the prime tenets of social work and associated research e.g. respect for the individual's rights, concern to represent the voice of marginalized groups and reflective practice. The attraction of the critical hermeneutic school of this methodology is that: 'it is often characterised as emancipatory research' (Lopez and Willis, 2004: 731) and the 'only approach which deliberately takes a participant's subjective perceptions as its focus' (Hallet, 1995: 55). These are interesting discussion points open to challenge. A research study can surely only claim to be 'emancipatory' if participants have either commissioned the research themselves, or been involved in the design or the carrying out of the project in a meaningful sense that is not tokenistic. There has rightfully been a growing demand, spearheaded by the disability pressure groups, for this kind of research activity and for its extension to all groups of service users (e.g. Clough et al, 2006). At best my study aims to represent the opinions and experiences of a cohort of service users, the majority of whom are recovering from an episode of illness or who have a serious long term condition, who would find it exceedingly difficult to either ask for, or be fully involved in, the running of a research project.

Phenomenology briefly outlined

Finlay from a background in occupational therapy suggests six principles common to the various types of phenomenology:

- '1. A focus on the life world or *Lebenswelt*
2. A commitment to description over explanation
3. The use of phenomenological reduction and *Epoche*
4. An attempt to retain a non-judgemental attitude
5. An acceptance of a role for interpretation
6. The concept of intentionality' (Finlay, 1999: 302).

Reduction and 'epoche' in phenomenological research means: setting aside or 'bracketing... any presuppositions, interpretations and prior understandings in order 'to try to see the world from another's point of view'. (Finlay, 1999:302). Others,

including Merleau-Ponty, have expressed the view that although the goal of many a researcher, to fully divest oneself of preconceptions is in fact an impossibility:

‘our goal cannot be neutrality, instead it should be close enough understanding aided by reflexive questioning...Language is always subject to interpretation and misinterpretation.’ (In Poindexter, 2003: 405)

Poindexter (2003:406) also discusses ‘the aims of empowerment, participation and understanding’ in social work research. To achieve those aspirations she suggests it is crucial ‘that the researcher invite people to construct their unique stance with us’. Although I did not discover Poindexter’s work until after the data generation phase of my study, I found this both a powerful and inspirational approach.

To sum up my perspective on the methodology for the study – I have sought a pragmatic and qualitative approach to the research topic (Patton 2002), so that in this instance:

‘Phenomenology is a paradigm which may guide the approach taken within interpretive research rather than a rigid restrictive method.’ (Hallett, 1995:55)

Researcher’s standpoint

It is interesting to consider my own position as a recent practitioner conducting a study of my former profession and area of work. Although I have inside knowledge of working practices which should be used openly rather than denied, and of relevant contexts and relationships, and I may retain some identification with the profession in question; it cannot be argued that this enquiry from an academic base, was part of, or conducted alongside, social work. As an outsider then to the latter, there was not the option to be able to work truly collaboratively or to feedback results directly into practice. The most I could aim for would be to relay my findings regarding local practice and policy in different ways or formats to the social work team and to their management, recognising that different principles were involved in disseminating outcomes to the separate layers of a local authority hierarchy. For example, hospital social workers would need to be able to have trust and confidence in the study, which is discussed again in Chapter 5. Furthermore while there is much to explore on the topic of the impact of research this is beyond the scope of the thesis.

From the standpoint of the ‘research minded practitioner’, Everitt et al’s work is useful in that it describes how critical, reflective and anti-oppressive principles can marry and inform both evaluative research and practice (Everitt et al, 1992).

Although I was in the position of a semi-outsider at the onset of fieldwork and unable to work with my old team as planned, I aimed to involve the practitioners from the beginning, and adapt Everitt's principles so that the team could feel that they owned the research. Unfortunately however, I would argue that in common with so much generalist literature about social work, the authors did not look at the particular challenges facing hospital teams. While I would like to have consulted with the practitioners from the start and gained their views on detail such as the interview agendas, access to them was not granted in the early stages, partly due to the pressures arising from the department's reorganisation. This set the tone for the rest of the project and I cannot claim that the social workers were equal partners in the study. Nevertheless I have come across few published studies on hospital social work that have set out or managed to achieve that principle (e.g. Gregory, 1997). Nevertheless the values that underpin social work were crucial in other respects, exploring hospital discharge primarily from the service user's position for example:

'The research minded practitioner would have particular regard for the view from below, according credibility to those who are often unheard, providing an opportunity for them to reflect in ways in which their views have been shaped in a society of inequality.' (Everitt et al, 1992: 138)

As I will detail in the sections below, I was able to eventually enter into an ongoing dialogue with the social workers and gave them regular feedback on the study's progress, incorporating their comments on my findings into the research, after checking out their opinions.

The role of the knowledge base for social work practice and its relationship to research was touched upon in the first chapter, including Malcolm Payne's work in which he drew attention to 'knowledge biases within a broadly conceived knowledge base'. He argued that it is more useful and relevant 'to see social work as in a continuous process of constructing and reconstructing professional knowledge.' (Payne, 2001: 134).

The choice and application of methodology therefore has its foundations in a critical perspective on the marginalisation of older people and the social policy drivers in relation to hospital discharge, amongst other issues. The impetus for the study was also derived from the desire to look closely at social work practice with older people. These factors have led to a concern to be able to explore aspects of the experiences of older people leaving the study hospital from 2004-6.

4.3 Research design

4.3.1 Methods

As referred to in the introduction to this chapter 4.1, in order to answer the research questions to achieve the aims of the study, three main types of data were generated during fieldwork. These comprised: taped and transcribed transcripts of interviews with individual service users and carers and focus group discussions, in addition to handwritten notes in a fieldwork diary recording thoughts on study progress and observations or memos following interviews and group sessions. Whilst the above section 4.2 outlined the overarching guiding philosophy influencing the approach to data generation, the following two sub-sections will look at the methods adopted and adapted to gather that data. They start with the rationale for choice of qualitative methods, then more specifically that underpinning interviews and focus groups.

Qualitative approach – interviews

From the outset it was clear, as detailed in 4.2.1, that the most appropriate approach to the enquiry was an interpretive or a naturalistic one, rather than a positivist approach. Above I have outlined the guiding approach to the study, which was phenomenological, and in particular a hermeneutical orientation. In terms of method, Van Mannen explains the hermeneutic interview which has: “a conversational structure: it is orientated to sense making and interpreting experiential meanings”(Van Mannen, 2002). To respond to the research questions, I therefore also wanted to start from the experiences of older people themselves with socially and psychologically constructed realities, as opposed to focussing on measurable, quantifiable facts. This is not to suggest that quantitative methods as another kind of human endeavour can be value free. Looking numerically at hospital discharge rates, for example, which the Department of Health review annually:

“may be used to measure success whereas, if understood within policy and procedural contexts, they might reveal evidence not of success, but of bed clearing operations or amnesties” (Everitt and Hardiker, 1996:5).

As discussed in the previous chapter some researchers have chosen to look at patients’ views by employing quantitative methods, perhaps using survey forms posted to a sample of people who have left hospital. Whilst many older people can respond to “tick box” type surveys (e.g. Lester and Jones, 1994) there are issues of visual and cognitive impairment to consider, which some studies combat with follow

up support to complete questionnaires. The problem of gauging older people's satisfaction particularly with the NHS has also been already referred to in the literature review (CSCI, NAO, CHAI, 2006). At one end of the continuum are studies, which may look at numbers or length or monetary costs of patient episodes, for example that clearly call for a quantitative approach.

To describe lived experience on the other hand, and older people's views of the quality of services, require more qualitative or inductive methods. I therefore chose to conduct semi-structured interviews with the aim of answering as many of the research questions in as much depth as possible while giving participants ample opportunity to raise their own concerns. The use of a looser semi-structured interview agenda also allowed a freer flow rather than keeping to a rigid list of detailed topics and to some extent may redress the researcher/participant power imbalance. As Jennifer Mason considers in the following:

If you choose qualitative interviewing it may be because your *ontological* position suggests that people's knowledge, views, understandings, interpretations, experiences, and interactions are meaningful properties of the social reality, which your research questions are designed to explore. Perhaps most importantly you will be interested in their perceptions.' (Mason, 2002:63)

Mason goes on to discuss the 'ethical goals' of the researcher (further explored here in 4.7) as to whether research interviews really are more empowering, 'fairer' and the extent to which it is intellectually or morally desirable to make the experience a 'therapeutic encounter'. Whilst the carers or relatives I would be interviewing may find it easier to talk about their experiences, I also asked myself whether older people would even wish or be able to converse in depth about leaving hospital. Would they be available and amenable to meet more than once and also ideally to view the transcripts of interviews held. The measures I took to enhance the chances of achieving these aims and the ensuing modifications to the research design are recounted in 5.3.

Focus groups with professional participants

In order to find staff opinions on the discharge process and to meet one of the study objectives, I decided that facilitating focus groups would be the most appropriate way of proceeding:

'focus groups can provide an excellent method for obtaining particularly rich information within the social context. This methodology can be used quite successfully conjointly with and to inform other research approaches which can provide a broader perspective.' (Slaughter, Pinfold, Flintoft et al, 1999: 5)

Not only would professionals hopefully be able to discuss their opinions with the support of colleagues in the group, but also debate between them would ideally trigger further reflections of interest which would go beyond the interview agenda and thereby fitting with the philosophy of the study, aiming to give as much power as possible to participants. Pragmatically use of time was also crucial, it was difficult enough to set up a group session in the lunch hour, let alone single interviews, and managers might not have released a comparable number of staff for an hour each. Questionnaires were considered but response rates may not have been as high and staff could have chosen not to commit their thoughts to paper. I am of course aware that group dynamics can be problematic if they serve the interests of the most vocal or strongest members, but for the most part, as described in 5.3.2 this did not happen. I found the guidance of Bloor (2001) helpful in this respect and prepared some ground-rules for the focus group based on this (see Appendix 6). I decided to follow Bloor's advice and keep the groups specific to each profession to allow for maximum comfort and minimum tension.

Field notes

Field notes took the form of notes made as soon as possible after every individual interview and focus group discussion. The aim of these were to recall impressions of the surroundings in which the interview took place, the demeanour of the participants, reflections on how the interview was conducted, how it flowed and memos to myself highlighting significant points of interest that either occurred in previous interviews with others or to check out in future interviews. Observations and references to conversations from my time spent in the social workers office for two hours every week over two years, ostensibly to pick up names of potential future participants were recorded in a research diary. Separate field notes were made following the presentation of research findings to the hospital social work team, to the local Age Concern staff group and then a sub-group of their discharge team.

4.3.2 Collecting the data

Planning and preparation

The impetus to undertake this study with hospital discharge as its focus came from the proposal to introduce the system of fines and reimbursements for local authorities, as discussed in Chapter 2. At that time in 2003, I was working in a team of care managers and had raised the possibility of looking at the effects of the legislation on service users' lives, as they left hospital. The team manager and colleagues were enthusiastic about the idea. I also contacted local user and carer organisations for their views on the project plans. I received two responses, both positive, one from each type of organisation. Unfortunately four months later, care management for hospital inpatients was switched from the community team to the one located on the hospital site. The repercussions for this study are discussed later. Meanwhile I set about gaining academic and ethical approval for the project. The milestones of the project's progress are outlined in Appendix 3. Copies of the documentation assembled for ethical approval for the University and under the (former) NHS Central Office for Research Ethics Committees (COREC) process can be found in Appendices 4-8. Once a favourable ethical opinion was obtained data generation from service users and carers could begin

The aim has been to produce thick description (Denzin, 1983) by conducting a small qualitative study using semi-structured interviews with service users and their carers where applicable, post discharge from hospital. I therefore devised interview agendas (Appendices 4 and 5) to capture the information needed to answer the research questions so that service user participants were asked about their experiences of being in hospital, their views of the quality of the discharge process, particularly regarding their own participation in the decision making, and about any involvement they had with a social worker during that period.

As outlined in 1.3 and above, I also wanted to explore the perspectives of staff involved in hospital discharge, including those of the social work team. After obtaining written consent from hospital trust managers, I therefore designed a provisional agenda for focus groups, which I circulated with the intention of presenting a loose framework, which participants could add to or conversely voice their objections to any part thereof. In order to answer the research questions outlined in 1.3, the agenda included questions on their views of older people and

carers' experiences, the role of social work and their own role in the process and how they found working together in the study hospital

The progress of the research study and the gathering of data: sampling, recruitment of participants, what actually happened and the challenges experienced, are reported in the next chapter, 5.3. In 5.3.8 there is an account of the completion of data generation and the detail of how the data was handled following this: conducting and taping interviews with users and carers and staff focus groups, transcription of interview recordings, interview summaries and checking back with participants and thematic analysis of the data. A discussion of the effectiveness of methods used in the study can be found at 11.2.2.

4.3.3 Approach to handling of the data

- *Thematic Analysis*

The form of data analysis applied to the interview and focus group findings was thematic. Thematic analysis of the data generated is consistent with phenomenological methodology (Morse and Field, 1996: 111) as outlined with reference to the study in 4.2.1 above and is an established method for analysing complex data (Dey, 1993; Riley, 1996). In order to search for themes in the data, I looked for reoccurring words, concepts and phrases within and between interview transcripts. From the literature search I had found other themes such as 'resignation' from a similar study (Reed and Stanley, 2000) that I was interested in looking for in my own. Furthermore it is important to note that I took time to think about what was within and underlying the data or what Van Mannen terms 'thematic reflection'. For him analysis: 'refers to the process of recovering structure of meanings that are embodied and dramatized in human experience represented in the text' (Van Mannen, 2002). Additionally in transcribing and then writing about the categories, further sense making occurred, which is a difficult cognitive process to explain.

To summarise initial categories were constructed from three sources:

- Responses to interview questions and research project aims
- Emergent issues raised by participants, found in more than one transcript
- Themes from other studies as reported in the literature review

I had originally intended to separate out the strands of presentation and analysis under two headings but this approach I found both detracted from the participants stories and took me further away from the original data. Therefore in Chapters 7-9 I have presented four major areas of emergent thematic groupings that I found relevant to the focus of the thesis, with the aim of trying to ensure clarity for the reader as to what is data, and how and where I have drawn inferences from it – the ‘writer’s voice’ (Holliday, 2002: 123). Chapters 6 to 8 and the first half of chapter 9 (to 9.5) belong to the service users and carers as they focus on their experiences, which I have presented in as fuller description as was possible with my own reflections and comments at the end of each chapter. The basis for reflection upon and interpretation of data will be:

- Whether similar findings from past research
- Participants’ testimonies – but making clear variation and contradictions
- My own professional experience
- Emanating from received wisdom – is a phenomenon ‘obvious’, less so, or counter-intuitive?

Evidence to back up my understanding will come from interview and focus group data, the literature, my research diary and field notes e.g. following interviews and of observations from time spent with the hospital social work team. This is further discussed in the next chapter (5.3).

In 4.4 below I discuss issues of validity in the research, which includes aims of trustworthiness, and credibility in the conduct and presentation of findings, closely linked to the ethical issues that follow in the final section. In the next chapter I will look at the tests of best practice applied to achieve those aims. For further detail on the organisation of data into three thematic areas of: loss and transition, decision-making and relationships, are given at the start of the data presentation chapters in 7.1.2 –3.

- *Development of illustrative case examples*

In Chapter 6 the illustrative case example of Teresa and her family is presented, three others can be found in Appendix 2. These illustrative case examples are seen as important both in contributing to descriptive background material for data analysis and presentation, but more crucially to the development of user and

practitioner knowledge: 'In essence we have only specific cases and context-dependent knowledge.' (Flyvbjerg, 2006)

The construction of these 'illuminative' type case examples are based upon the work of Robert Stake who explained that he 'draws from naturalistic, holistic, ethnographic, phenomenological and biographic methods' (Stake, 1995) hence applicable to the approach to this research. In other words, for Stake : 'the qualitative researcher emphasises episodes of nuance, the sequentially of happenings in context, the wholeness of the individual' (Stake, 1995:xii) Patton develops Stakes' methods in his own style and usefully summarises the 'process of constructing of case studies' into three steps (Patton, 2002:450) which I have followed:

- Assemble the raw data
- Construct a case record
- Write a final case example narrative

In the past the use of case studies or examples was often dismissed as an inferior 'soft approach' to investigations because of the focus on small, sometimes unrepresentative samples. However it seems that there has been a renaissance for the method to the point that it has been argued that case example exemplars are essential to the successful qualitative inquiry (Flyvbjerg, 2006). To sum up the latter's argument briefly: this is because of the way in which via a case study or example the investigator can gain a thorough understanding of the participants' lives and then present a rich or thick description to the reader. Flyvbjerg convincingly dispensed with five common criticisms of case studies (Flyvbjerg, 2006); although it is arguable that a well-executed ethnographic study in which the researcher had immersed herself in a setting for example, could achieve a similar outcome.

During the research design phase I had considered using a case study approach to the whole project, as an alternative method. The conventional definition of a case study is of a 'bounded system' and that can be about individuals, places, events or processes, to name the most common types. I considered using the last two types in relation to hospital discharge, but I believed that instead the focus should remain with the first – the actors or the older people and their families. However I realised

fairly early on as I set about gathering data that I would not be in a position to use a variety of sources, to interview every service user's relative, social worker, key nurse or home care assistant for example to form truly comprehensive and comparable case studies. Hence the narratives that follow are individual illustrative case *examples* of service user and carer participants, organised according to the themes used in Chapters 7-9 of the thesis. The approach to selection of cases is discussed in 6.1.1 prior to Teresa's story as the first illustrative case example.

4.4 Validity of the research

In terms of seeking to ensure the quality of data generated and the credibility of its interpretation and analysis, 'validity' is still the word that comes to mind.

This is used perhaps as an umbrella short-hand term with regard to qualitative research since for many years it has been viewed as more applicable to positivist paradigms and quantitative methods (Lincoln and Guba, 1986). As an alternative approach to evaluating the quality of qualitative research: 'trustworthiness' including 'credibility' and 'transferability' has been proposed (Patton, 2002). From a social constructionist perspective rather than looking for an 'answer' or objective truth it is argued that there are only multiple realities. However as Patton commented:

'Qualitative inquiry can present accurate data on various perspectives including the evaluator's perspective without the burden of determining that only one perspective can be true.' (Patton, 2002: 578)

The latter point is consistent with the phenomenological approach of describing the lived experience of participants, which is not concerned to verify their version of events with another party, but accepting *their* reality. Both trustworthiness and transferability are relevant here, that I need to be honest, open and fair in the analysis of the data that are then not used to confirm claims that suit mine or anyone else's perspective. Nevertheless if time and effort from participants are required and the research is going to be of some utility, the transferability test has to be passed. Patton is of assistance again in his description of extrapolating rather than generalising from data: 'Extrapolations are modest speculations on the likely applicability of findings to other situations, under similar but not identical conditions.' (Patton, 2002: 584)

Triangulation

Related to 'validity' is the concern of some researchers to 'triangulate' research findings or 'the use of two or more methods of data collection in the study of some

aspect of human behaviour' (Cohen and Mannion, 1989: 269). In striving to produce robust data analysis, acceptable as academic research I had originally believed that focus group findings with a third group of participants, in addition to those generated from service users and carers, could be considered as both method and data triangulation. On reflection however after further reading and discussion of qualitative approaches, triangulation appeared to be an inappropriate concept in the context of the philosophical underpinning of my study. Originally triangulation as a technique was conceived as a way of reducing the bias that could arise in the operation of a single method (Blaikie, 2000: 263). The search for consistency or verification among research findings 'assumes an objectivist ontology' (Blaikie, 2000:264) i.e. not akin to that underlying my study. Instead, both quantitative and qualitative researchers now argue that the different insights or findings that emerge from using different research methods are complementary (Bannister et al, 1994; Blaikie, 2000). However, where different methods are used and common findings are generated, that can serve to strengthen any conclusions drawn from the data. The former perspective has more relevance to the approach to findings from my study.

Of even greater importance, and closely linked to the trustworthiness or credibility of the researcher, are the ethical issues arising from the project.

4.5 Ethical issues

The following ethical issues arising from this type of study and its contact with some vulnerable participants had to be addressed:

- 1. Reassurance for ALL potential participants** that taking part in study was entirely voluntary at every stage. 'Process consent' was important - rather than seeing consent as a one off event. Some participants were also unable to actually sign (and read) the consent form. I always began the interview with service users and carers by asking permission to start talking to them about their experiences and depending on length of discussion checking at least once with them that they were happy to continue. I also sought permission to tape our conversation and to use the content for my study, asking if any changes or withdrawal of speech were wanted and whether they would view copies of the transcript once prepared. Only two relatives and one user agreed to see the transcripts following the offer. I sent all staff groups copies of their discussion transcripts.

2. **Confirmation for informants that choice to participate** was not linked to service provision or delivery. Care was taken to ensure participants understood this important point, particularly as the researcher was at times mistaken for their social worker. Nevertheless, I became wary of overdoing reassurance and checking out, as there comes a point when it can seem counterproductive and induce uneasiness with service users feeling perhaps there was something to worry about.

3. Confirming that service users referred by social workers for potential participation, and their carer or relative if applicable, were able to give **informed consent**. I referred to this above and particularly the tendency of some participants wanting to please and be helpful. With a few service users it became clear during our introductory meeting that they had some cognitive impairment and whether they were able to give informed consent was debatable. In those situations, we had a conversation if they wished to about any subject they were comfortable with, but I did not proceed with attempting to explain the study or seek their consent to take part. This happened twice. However the process of engaging with people is not an exact science and for a further two participants once I came to know them better and they relaxed in the interview, their repetitive speech and evident memory loss suggested early stage dementia to me, although my judgement was in line with the social worker's that at the time they had been able to give informed consent to participate. Fieldwork predated the Mental Capacity Act 2005 reforms with their principles and guidance for third party consultees to act on behalf of research participants.

4. **Taking care** that participants were not distressed, too tired or unwell during interviews. Linked to process consent, this was a matter of both checking out with participants verbally and also picking up non-verbal indications of pain or discomfort and fatigue. At the start of the interview I would ensure that the service user participant had a drink to hand and I carried a spare bottle of water for them in case it was difficult to find a convenient source of drinking water. Without causing offence or invading privacy it was also important to try and make sure participants were as physically comfortable as possible, could stop at any time to use WC and so forth. Non-physical or emotional comfort was vitally important too, for example knowing when participants did not wish to continue either with the interview or with a particular topic that was upsetting for them, and I refer to the latter from time to time during the presentation of the data

5. Preservation of anonymity, and ensuring privacy. Care had to be taken with storage of tapes and transcripts and that names of participants are not in the same place as codes. Following transcription, the tapes were locked away at a separate site, at the university. No actual person or place names have been used in the thesis or any other publication to avoid any identification.

Ensuring privacy during interviewing can be difficult in hospital or care home setting. The first service user participant I met on the ward did not feel like leaving his bed to talk to me in a private room. Similarly one care home resident insisted on staying in her chair in the lounge right by staff kitchen door so there was neither quiet nor confidentiality for the interview. Staff asked one other resident in the lounge if she was willing to move for a while, which she was and the third person was fast asleep for the whole of our discussion

6. Treating all participants with respect and dignity.

At the first meeting I always checked with participants which name they wished me to use, rather than automatically addressing them by their forenames. In Chapters 6-9 I often refer to situations when sensitive issues came to the fore, e.g. regarding bereavement, when it was not possible to probe about participants' experiences, as their needs were paramount. Judgements therefore had to be made about stopping interviewing or taking other appropriate action and continually re-assessed with each participants.

7. In cases where informants have **communication difficulties** or English is not the first language, ensuring that their views can be heard e.g. via an interpreter. A few participants were sight or hearing impaired but not to the point of requiring additional equipment. For all of them English was their first language. Nevertheless, I realised that I did not always express myself clearly to participants who did not understand what I had said and I then had to rephrase questions or points.

8. Reciprocity. Above I have written about **stepping out of the researcher role**, when participants needed advice or for follow up to be carried out e.g. by contacting their social worker or care home manager after the interview. These situations had to be carried out with sensitivity and if a participant became very distressed I would have sought further advice from appropriate quarters e.g. social worker, family, GP with their consent. Reciprocity does not just mean completing the thesis that is then hidden away in a university library but thinking about more accessible forms of

dissemination such as journal papers and conference and user group presentations. This principle of disseminating and sharing the findings of the research are the very least that can be done to acknowledge the time given by participants particularly when no fees are paid for this.

All the above had to be addressed by the researcher herself who as well as being aware of these issues was bound by the codes of ethics governing University and social work NHS related research.

4.6 Conclusion

As much as anything else this chapter has been about a PhD student's 'voyage of discovery', from learning about different philosophical approaches, methodologies and methods to what it is to be a social work researcher rather than practitioner. I quickly realised that much of the conduct of a research project is beyond one's control, for example changes to local and central government policy and organisation, and having to comply with procedures set up as they were then, principally for medical research. The next chapter will focus on describing the setting for the study locality and continue the voyage begun above: the process and progress of data generation in that locality.

5 Study locality and data generation

5.1 Introduction

This chapter will describe the area where the study participants lived, with some demographic information and basic health indicators. It will focus upon the social services department and the study hospital where the social work team was housed. The chapter will briefly sketch the study backdrop - a town that has below average numbers of people from minority ethnic groups, the unemployed and reported poor health suffered by its residents. The local authority complains annually about an inadequate income settlement from central government but it has also historically spent less proportionately on older people than most other councils of similar size and nature. The description will also briefly look at performance of health and social services in governmental terms.

The information about the locality was drawn from:

- Statistics available from the General Household Survey,
- The SSI Inspection of 2001 and more recent local authority progress reports
- The acute hospital trust's data from annual reports and the Patients' Experience Team
- The independent Healthcare Commission's assessment of the hospital trust.

The chapter then considers the process of data generation, some of the issues and challenges encountered along the way and the analytical pathway followed in order to address the research questions which, in brief, was achieved by:

- Conducting 29 interviews of a sample of service users who had left hospital and their carers where appropriate and permissible
- Facilitation of five focus groups with key professionals involved in hospital discharge
- Weekly visits to the hospital social work department 2004-6
- Keeping a fieldwork diary

The details of the above can be found at 5.3 below.

This chapter sets the scene for the data collection component of the research project and acts as a bridge between background information and the presentation of the findings.

My study was conducted with older patients and their families following discharge from a large acute district hospital in a medium sized northern English town, and with members of staff working in the hospital. In order to meet requirements for anonymity of participants, no further identifying details can be given.

5.2 The study locality

5.2.1 The setting for the research, from where participants originated

Starting with some basic demographics, the town's population in mid 2004 was 183,000. About two thirds of the population live in the urban centre of the area, the rest in satellite villages or in the rural parts that are surround the town and go beyond its boundary. Only about 1% of the population are from minority ethnic groups and very few of those are currently elders. Table 5.1 shows breakdown of the older population in the locality by age range, and a projection up to the next decade:

Table 5.1 Study locality populations by age and projection

Age group	2001	%	2016 projection	%
<65	150,464	83	154,078	80
65-74	15,804	9	21,000	11
75-84	11,032	6	11,700	6
85>	3,794	2	5,100	3
Total	181,094	100	191,878	100.00

Source: SSI Inspection of study locality Older People's Social Services 2001

This is an unremarkable place in that unemployment is well below the national average and deprivation confined to very few pockets in the town. Wages however are generally low with many jobs being in service industries, little manufacturing activity remains, but as in many other areas, house prices have continued to increase, certainly up to early in 2008. While these factors may not affect older people directly, they certainly impact upon younger family members and the increase of property value has contributed to the past sale of many care homes.

The phenomenon of older 'equity rich, cash poor' residents living in often unsuitable and inadequately maintained housing is also evident.

About half of the older population of the town live in single person households. The number of residents receiving home care fell slightly however in 2004-5 to 1,445. As Table 5.2 shows, the percentage of people with a long-term illness and poor general health in the area of study is below the national and regional average, as is the percentage of those who provide unpaid care 20-50 hours a week. The data set below shows level of general health and unpaid caring in the town, and region compared with the country as a whole during the period of the study..

Table 5.2: Health and provision of unpaid care in the study local authority, 2004-5

		Local Authority	Region	England
All People	No.	181094	4964833	49138831
People with a limiting long-term illness	No.	30064	967284	8809194
	%	16.6	19.48	17.93
People of working age with a limiting long-term illness	No.	12506	440037	4014005
	%	10.96	14.55	13.29
General health: Good	No.	127242	3324553	33787361
	%	70.26	66.96	68.76
General health: Fairly good	No.	39365	1129206	10915594
	%	21.74	22.74	22.21
General health: Not good	No.	14487	511074	4435876
	%	8	10.29	9.03
All people who provide unpaid care	No.	17009	518211	4877060
All people who provide unpaid care: 1-19 hours a week	No.	12478	345491	3347531
	%	73.36	66.67	68.64
All people who provide unpaid care: 20-49 hours a week	No.	1520	58856	530797
	%	8.94	11.36	10.88
All people who provide unpaid care: 50 or more hours a week	No.	3011	113864	998732
	%	17.7	21.97	20.48

Source: General Household Survey (KS08) 2004-5

5.2.2 Social services

Performance and inspection

In terms of expenditure the 2001 SSI inspection report on the inspection of social services, noted how the local authority spent 'well under the national average per person for older people' and was the third lowest spender for residential and general care in the comparator group of 16 councils. Anecdotally it was always claimed that the town had inherited both a flat management structure and a relatively low service provision from its predecessor regime of a county council. For example unlike a neighbouring city social services department there was:

- No day care for older people apart from limited places within residential care homes
- Only one care home offering specialist residential or respite provision under the 'elderly mentally infirm' (EMI) registration category
- A limited respite scheme for older or disabled people to reside temporarily with approved carers and no provision for the latter to stay in service users homes to give short breaks for informal carers (apart from agency sitters paid for privately)

And:

- Rapid Response home care service was no longer free of charge for two weeks after leaving hospital from 2006, when it was claimed it was an unnecessary cost to the LA as delayed discharges had reduced
- Subsidised domestic support for those on low incomes was removed in 2001, as has happened in other local authorities

Furthermore the council decided in 2005 it would only meet 'moderate' to 'critical' needs under the Fair Access to Care arrangements (DH, 2002b) and it has been proposed in 2008 that the threshold be further raised to the meeting of 'substantial needs and above' only. Other cutbacks to the service provided to older people from 2006/7 included policies which meant that requests for help with shopping are referred to Age Concern's Internet scheme, and requests for home care assistance with bathing have to be approved in writing by a district nurse or GP.

Returning to the 2001 SSI inspection of the study local authority's social services for adults, the summary states:

'The inspection found that joint planning of health and social care was in a state of flux and there was a significant problem of delayed discharges from hospital and waiting lists for some services. Nevertheless, there were high levels of user and carer satisfaction and a number of services were helping to promote independence. There was a user-friendly customer advice service and a generally prompt response to referrals by the care management teams. However, assessments were of inconsistent quality and multi-disciplinary processes were poorly developed. Charges for services were sometimes excessive. The department needed to develop its commissioning strategy and particularly to address the shortage of residential and nursing home places.'

The inspectors also reported on a shortfall in the funding of placements for adults and insufficient acute and intermediate care beds for the hospital trust.

'Delayed transfers of care' were singled out as major problem for health and social services to address. Additionally, there were indications of a poor relationship between the two bodies with, it seemed, 'no shared direction of travel' to address the challenges they faced. The fact that delayed discharges did decrease following reimbursement was probably due to the re-focussing of resources onto the area, including the growth in intermediate care and rehabilitation facilities, combined with older people facing speedier discharge from hospital. However, simply pointing to a reduction in numbers of delays, can mask the effects on older people and their families (Henwood, 2006) as shown by the complex interplay of issues arising from this study's findings, described and discussed in Chapters 6-9.

The abolition of the SSI reporting structure has meant that there are no current inspection reports to draw upon and compare with 2001. Between 2002–7 social services for adults in the locality has been awarded two stars by CSCI under its rating system, but dropped to one star after the last assessment of performance under this system for 2008. While independent sector nursing homes have continued to close in the area, as indicated above, there has been investment in intermediate care and rehabilitation facilities. Additionally transitional care beds have been commissioned in two nursing homes although one is situated at the edge of the north of the town and the other is in a rural community some miles to the north-east causing hardship to those relatives from the south and west travelling on often inadequate public transport. General progress in tackling delayed discharges from a numerical, administrative perspective has been achieved, in the words of the 2006 Delivery and Improvement Statement, to: 'the level where social care has contributed to the delay has remained continuously low'.

In terms of the intentions of the local authority from 2006 onwards, the three priorities for social services are:

- Re-commissioning of home care
- Increase in extra care housing and EMI or dementia care provision
- Planning for expected extension of reimbursement from the non-acute sector

The rolling out of the Single Assessment Process had not begun when the fieldwork was conducted.

Structure and organisation of the hospital social work team

Social services within the study locality share a joint directorate with the housing department. In 2003 just prior to fieldwork commencement, the older people's and physical disabilities' teams merged to form general adult teams that were then split geographically into four. In the hospital team, there were nine social workers, one unqualified worker and one reviewing officer in post when data gathering finished with two posts vacant. Although the number and composition of the team fluctuated throughout the two years of contact, a constant core of about six experienced staff was there throughout. Four 'elderly medicine' wards are served, in addition to two orthopaedic wards, stroke and assessment units. Older patients are of course to be found on most of the other wards, many of who may be the responsibility of elderly medicine, known as 'outliers'. Referrals for social care are channelled from the public, hospital staff or others through the customer services office based close to the outpatients department and are then screened by the team manager prior to allocation. Social workers are attached to particular consultants and try to attend multidisciplinary team meetings whenever possible, but are no longer based on the wards to take referrals directly. As has been found in other studies the hospital team had little contact with community counterparts, apart from on a 'case by case' basis (Penhale, 2000).

In 2001 the hospital social workers carried out initial assessments, referring those in need of care management onto the community team, but this changed in 2004 with the hospital team taking over full responsibility unless a community care manager was already working with the inpatient. The SSI inspectors commented in 2001 that

the arrangements did not contribute to effective discharge planning and that hospital staff were frustrated with numbers of older people waiting for services, and were sometimes opting to bypass social services altogether. However the hospital team otherwise operates similarly to pre 2001 and the following comments from the SSI inspectors were similar to those made to me four years later by doctors and some therapists, that:

‘...social workers were no longer attached to wards....Health staff were expressing dissatisfaction that social workers were not as actively involved in the multi-disciplinary clinical teams as they used to be. They felt that this hampered communication, particularly in complex cases where it was vital.’

While in general turnover of social workers in the study local authority remains low, this may simply reflect a lack of similar job opportunities within easy reach of the town and its comparatively pleasant environment. It seems recruitment and retention of home care and residential staff continues to be problematic.

5.2.3 The study hospital

Origins of the hospital

The general hospital opened its doors on its current site in 1976 and is a typical glass and concrete box structure of its time. Psychiatric services are housed in a separate older building next door. Building work is ongoing adding new facilities and updating original wards and clinic areas. Prior to 1976 there were acute, geriatric and maternity hospitals on separate sites. Older people continued to be treated in three separate hospitals until Harold Wilson opened a specialist geriatric hospital in 1979, which included rehabilitation and day units (Webb, 2002). This closed in 1996 and the amalgamation of facilities saw a reduction in number of beds for older people. The hospital serves a population of 300,000 that extends in a 20-mile radius from the town centre and encompasses a neighbouring city. Its boundaries overlap into two other local authorities as well as the local authority whose social services team were involved in the study – which is responsible for the majority of patients.

The study hospital became an acute NHS trust in 1992 and was awarded foundation status in 2006, following the award of three stars in 2005 by the Healthcare Commission. The trust was keen to be a foundation hospital the year before but lost a star, which was partly blamed on higher than average numbers of delayed discharges. The other important new development in 2006 was the addition

of a PCT commissioned privately owned treatment centre, the presence of which has created some new difficulties as outlined in Age Concern's comments in Appendix 11.

Performance of the hospital trust

Under the new Healthcare Commission ratings the hospital was assessed as having GOOD quality services, although use of resources were labelled as WEAK in 2006. Regarding NHS performance targets the trust achieved 84% of discharges 'on time'. The Patient Experience Team in the hospital trust monitor complaints that are made formally and resolved, as well as compliments and enquiries to the Patients Advice and Liaison Service. During the period of data generation for the study, in 2004 there were 32 complaints received from patients or their representatives regarding stays on the elderly medicine wards, in 2005 the figure was 27, broken down in the table below.

Table 5.3: Numbers and types of complaints re Elderly Care received by the study hospital's Patient Experience Team 2004-6

Type of complaint	2004/5	2005/6
Concerning discharge	3	4
Communication/provision of information	5	1
Care and treatment of patients	21	18
Other	3	4
Total	32	27
Total no of inpatient/day-cases	74,391	77,959

I was also able to look at the enquiries received by the Patient Advice and Liaison Service between October and December 2005. Only 18 enquiries were instigated regarding elderly medicine, the sixth lowest category out of 14 subject areas, the highest number being 79 on matters external to the trust, followed by 48 for general medicine and 35 for orthopaedics. Enquiries on social services issues are grouped together with 'benefits' and 'voluntary agencies' so this is not a very helpful indicator for our purposes. Compliments flow into the trust however and exceed complaints by a long way – for the period July – December 2005 Care of the Elderly were reported as attracting 400.

Scrutiny of the minutes of the Trust board monthly meetings and the annual report for 2005-6 revealed that they are interesting for what they do not include. Elderly Medicine and related matters rarely featured in the minutes for the past 12 months. The local authority is referred to once regarding children's services and paediatrics. In the Trust's annual report while voluntary organisation provision is briefly outlined, there is no mention of social services. The latter's department is well established within the hospital and includes a customer service reception open to the public as described above and specialist social workers such as for the renal unit and HIV.

Some points of interest from a local voluntary organisation giving their perspective on how the hospital and local authority serves older people will be referred to in the thesis and can be found in Appendix 2.

5.3 Data generation

The site for the research study was selected because of prior knowledge of the acute hospital and existing contacts with the local authority social services. It was therefore possible to gain access to professionals and service users as potential participants for the study as detailed in 4.4.1. The rest of this chapter follows on from Chapter 4's foundation of guiding philosophy, appropriate methodology and methods, to elaborate upon the resulting outcomes of the approach to the research questions.

From the study hospital and locality described above, a total of 61 service users and carers were referred to me as potential participants by the hospital social work team. As is indicated by the Table 5.4 below, the lower point of target for interview numbers (15-20) was exceeded. In order to access this group of older patients who had received a social work assessment, in addition to meeting the criteria outlined below, purposive sampling was adopted. This theoretical sampling approach is a recognised and important tool in qualitative research or:

'selecting *information-rich* cases for study in depth. Information rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the enquiry...' (Patton, 2002: 230).

Table 5.4 Outcomes and numbers of referrals to the research project

Referrals	No.
Service users interviewed*	19
Close relatives/carers interviewed	16
Refused or withdrawn after initial contact	12
Inappropriate referrals	6
Deaths before contact	5
Wanted to talk over telephone only	2
Unable to contact	1
TOTAL	61

***5 service users were interviewed jointly with their corresponding 6 carers, see p.108 for details.**

5.3.1 Recruitment of sample

Recruitment of potential service user participants to the study

Hospital social workers agreed to make an initial approach to individuals on their caseload, who were identified as potential participants. They were also in an advantageous position to know whether there was any reason (e.g. recent bereavement) why it would be inappropriate to contact a service user for this purpose. Sampling inclusion criteria were as follows, that the person was:

- An in-patient over 65 years old
- Had contact with hospital social worker or care manager
- Not in the terminal phase of illness or having communication difficulties or a condition that would prevent participation in an interview or the ability to give informed consent to take part in the study.

The reason for adoption of these particular criteria is probably self-evident. The first two are to enable the aims of the study to be achieved. The last one was used for ethical and practical purposes - an service user known to be terminally ill was deemed to have the right *not* to be approached for a research study, and may well be too ill to participate. It was also crucial that all participants were volunteers and could understand what giving consent meant in accordance with (the former) COREC, university and social work research governance.

Recruitment of carer participants groups A and B to the study

With the agreement of informants their close relative or carer if applicable, were contacted to ask if they would like to take part in the study. So for these potential carer participant there were three inclusion criteria:

- Named by a service user participant as their carer, relative or significant other.
- Service user gave permission for researcher to contact this person as indicated on user participant's consent form.
- The carer not in the terminal phase of illness or having communication difficulties or a condition that would prevent participation in an interview or the ability to give informed consent to take part in the study.

If they were agreeable the carers or relatives were approached in the same way as the service users, with a telephone call followed by an introductory visit and the giving of information sheets and consent forms. These particular carer participants formed a group I called Carer Group A.

In order to widen the sample to gain insight into the experiences of families of those older people whose relative had been discharged from hospital but to whom I did not have access due to cognitive impairment, an amendment to the recruitment plan for the study was made, referred to below in 5.3.7.

The inclusion criteria for these potential participants were therefore:

- Carers or relatives of patient over 65 discharged from hospital but that patient was unable to give informed consent to participate in the study
- Patient known to hospital social worker
- Hospital social worker agreeable to complete a assent form stating that participation would not harm the patient
- Carer or relative not in the terminal phase of illness or having communication difficulties or a condition that would prevent participation in an interview or the ability to give informed consent to take part in the study.

Hospital social workers made the initial contact with the carer or relative and with those persons permission, completed assent forms and passed names to me. Carers were then approached in the same way as the relatives or carers above,

asked if they wanted to participate in the study, given information sheets and consent forms if they were willing. Those recruited who fulfilled the above criteria formed a smaller group of carer participants named Carers Group B to distinguish them from Group A, who were recruited via service user participants as described above. Full documentation, which accompanies the official request to the social workers, including information sheets and assent form are in Appendix 8.

Recruitment of staff involved in hospital discharge of older patients to study

In order to convene the staff focus groups I initially obtained permission for use of staff time during working hours from the senior manager or budget holder within the acute trust. This was obtained fairly quickly and having received ethical approval for information and consent sheets and the interview agenda, I then approached the line managers at the hospital, or the senior consultant and social work manager for the doctors and social workers respectively. Line managers asked for volunteers from their staff to take part. I sent background information on the study in addition to the aforementioned documentation and offered to meet staff in advance to answer any queries and to talk further about the research project and the focus groups. In actual fact none of the managers agreed for me to come and meet staff prior to the groups or seemed to have any questions.

Inclusion criteria for staff were that they had volunteered to participate and that they were professionals working in the study hospital with older patients prior to discharge, whether that be in multidisciplinary assessment, therapeutic interventions or discharge planning etc. Personnel were further formerly asked for their permission for focus group discussions to be recorded prior to sessions.

5.3.2 Conducting the interviews and focus groups

Individual interviews with service users

An introductory discussion was held with each potential participant with their agreement, and if they were willing to hear more, the project was fully explained and the information sheet left with them for deliberation. I then telephoned one or two days later to provide further clarification, answer any queries, and providing the participant was happy and able to give informed consent, the interview was arranged. Interviews lasted between 20 minutes and 80 minutes approximately, with time spent beforehand and afterwards, to respond to any questions and on informal conversation depending on the requirements of the individual. All were taped with

the permission of the participants, apart from one when the recorder failed, and then later transcribed verbatim.

In practice the introductory visit to explain about the research and what I was asking for, often took as long or longer than the actual interview. Service user participants spoke at length about their backgrounds, family relationships and wider events when we did not have to start with form signing and the setting up of the tape equipment. Most service users were keen to tell me about their early lives, their work and children which for the majority were often hard periods physically and economically, but were happier reflections in the main than the more recent past of ill health. It was also a good non-controversial start to forming an, albeit brief, relationship with these service users. For example one woman recalled as a child seeing World War 1 planes flying above and another man had loved his job working for the Royal Mail on the night mail trains that used to run.

Carers' participants tended to have less time available than the users, and were perhaps slightly more wary. Half of the carers had retired or were not working due to sickness or disability. The rest were mid career and/or bringing up a family of their own. It is also interesting to note that two of the service user participants (U15 and 16) who had been in hospital, were also carers of their spouses and a third (U11) had cared for his wife until her death. Five service users were interviewed jointly with their carers at their request, as indicated on the Table below: UO10 with CO6; U12 with CO7; U14 with CO9 and CO10; U16 with C16; and U19 with C15. The remaining service users and carers were interviewed individually and separately. As the service users were interviewed first – apart from the carers of patients with cognitive impairment in Group B, they often provided brief background information about their carers and other family members. Referrals of potential carer participants to Group B who would be eligible under the extended criteria came in slower than anticipated, and this resulted in only a further four interviews taking place.

Characteristics of sample interviewed

Table 5.5 below shows the main characteristics of the service user sample.

Table 5.5 Characteristics of service user participants

Participant¹	Sex	Age²	Weeks in Hospital	Current Location³	Council Funded⁴	Lived alone Pre-Admission?	Carer/Relative Interviewed⁵
U01-Fred	M	86	12 +	Died N/H	Yes	With sister	No
U02-Flo	F	94	20	Res Home	Yes	Alone	Yes. C01 singly
U03-Mona	F	74	53	N/Home	No	With son	Yes. C02 singly
U04-Jessie	F	85	<2	Own home	N/A	Alone	No
U05-Eric	M	86	20	Died N/H	No	Alone	Yes. C03 singly
U06-Carrie	F	89	12	Supported Housing	N/A	Alone	Yes. C04 singly
U07-Edith	F	75	8	Res Home	No	Alone	Yes. C05 singly
U08-Hilda	F	79	12+	N/H	No	Alone	Yes. C08 singly
U09-Gertie	F	90	4	Res Home	No	Partner recently died	No
U10-Harry	M	77	20	N/H	No	With partner	Yes. C06 jointly
U11-Bob	M	93	36	Res Home	Yes	Alone	No
U12-Sid	M	79	12	Res Home	Yes	Alone	Yes. C07 jointly
U13-Sam	M	81	6	Res Home	Yes	Alone	No
U14-Teresa	F	78	16	Own home	N/A	Alone	Yes. C09/10 jointly
U15-Keith	M	85	22	Res Home	Yes	With partner	No

Participant ¹	Sex	Age ²	Weeks in Hospital	Current Location ³	Council Funded ⁴	Lived alone Pre-Admission?	Carer/ Relative Interviewed ⁵ .
U16-Peter	M	78	2	Own home	N/A	With partner	Yes. C16 jointly
U17-Annie	F	78	2	Own home	N/A	Alone	No
U18-Stephen	M	67	3	Rented flat	N/A	Alone	No
U19-Len	M	80	3	Own home	N/A	With partner	Yes. C15 jointly

Notes:

1. All participants white British.
2. Age at time of interview [2004-2005]
3. Location of service user participant at the end of fieldwork: N/H = Nursing Home, Res home = Residential Home, Own home = service user participants who returned to former address with home care input.
4. Council funded = care home fees partly paid by LA as non-property owner or savings below threshold
5. Some carers/ relatives unavailable for interview, due to living far away or service user participants did not want me to contact them; too busy etc. 'Singly' indicates where carer interviewed individually i.e. separately from service user. 'Jointly' indicates where carer(s) interviewed together with service user.

Post-interview activity and reflection

Immediately after each interview I aimed to spend time reflecting on the session and made notes about the circumstances of the interview including any external factors. For example one interview occurred outside a noisy staff kitchen, another in my car, at the insistence of the older person and a relative respectively. Relevant detail on the behaviour of the individual, my own as researcher and comments on our interaction were also noted. Later, usually the same day, I would play the tape recording back in order to pick up additional points I may not have been aware of at the time. In consort with the reflexive methodological approach, it was necessary to incorporate issues within future interviews raised by participants themselves, particularly as it had not been possible to conduct a pilot study. For example in the second interview with a carer I had been struck by a comment made almost in passing, but which seemed to me was actually of significance to the narrator regarding *how* he learned that his mother would not be able to return home to continue living with him. Moreover it was crucial to try to learn from each interview in order to try to improve upon my performance for the next one. Use of language is a key consideration. In the very first interview of the study, for example when I asked a service user about any 'help' the social worker had given him, he interpreted that to be a question about the home care support he had received in the community.

Some service users were either very private in their attitude and hence brief or circumspect in their responses. Moreover a few were clearly still distressed by what had happened to them and it would have been unethical to probe further on this and other sensitive issues. During the longest interview, with participants U14 and C 9/10, they had been very open about their views on all aspects of the hospital stay, the discharge and services etc., and I therefore felt it appropriate to ask them about the issue of 'emotional support' which had arisen in the interview with U10. There were only two other participants who it felt possible to raise this with.

Service User participants' understanding of the researcher's role

In many cases it was apparent that the service users were unaware of the nature or definition of research, although I tried to give as full an explanation as they wanted. In a desire to be open I had told participants that I had been a practising social worker, and I realise that many service user and carer participants heard the latter words and retained the title 'social worker' as a role with which they were familiar as opposed to that of researcher. When I asked two separate service users about their experiences of the hospital social worker, they looked quite surprised and replied

had it not been me that had had worked with them whilst they were inpatients? One of them implored me to let her stay in the transitional care home she was in.

Perhaps I had a similar appearance to some one they met before. One of the relatives at the very end of the interview asked me what I was going to do about certain aspects of the care his Aunt was receiving and could I discuss this with the home manager? I explained that it would be better for him to speak to staff directly, but I did agree to pass his concerns on at his insistence. Luckily I had worked with that particular care home as a social worker, an outside researcher might have been in a more difficult position. These instances illustrate how people might make sense of the title 'researcher' when coupled with that of 'social worker'. With another group of service user and carer participants who were more sceptical or assured, one can speculate that the outcome might have been very different.

Interviews with carer participants

In contrast to the above-mentioned interview with a relative that was not the most satisfactory of discussions, the other interviews involving carers/relatives all yielded rich data in my opinion. The two longest interviews with the densest text involved both relatives and service users. In both, the carers were able to assist the service users who had dysphasic speech following a stroke in expressing their opinions, even when they were at variance to their own. However it is obviously not possible to know how any of these participants would have responded individually by themselves, and some less healthy relationships could have had an adverse effect upon a joint interview. All the carer/relative interviewees were willing and able to talk about the interaction with social workers apart from two. One said she had only had a telephone conversation with a social worker, and the other had not had dealing with social services although she implied she had. In the latter case, her sister seemed to have been the sole communicant with them, and I was later able to talk to her on the telephone.

Focus discussion groups for staff

Focus discussion groups were organised by separate occupational groupings of discharge liaison nurses, occupational therapists, physiotherapists, doctors and social workers involved with medicine for the elderly wards. The aim of facilitating the discussions was to obtain opinions of different staff groups of how discharges were operating, multidisciplinary activity and the effects of delayed discharges legislation upon their work. Table 5.6 shows the gender composition of each group constructed according to profession:

Table 5.6 Compositions of staff focus discussion groups

Profession	No. *	Female	Male
Social workers	10	9	1
Physiotherapists	8	7	1
Occupational Therapists	6	6	0
Discharge liaison sisters	2	1	1
Doctors	3	1	2
Total	29	24	5

*= Number of participants per focus group

N.B. Ethnic origin of all participants was white UK

A loosely structured interview agenda was circulated to the focus group participants in advance of the sessions to see if there were any issues that they wished to put on the agenda and to gain their opinion of the topic areas I had suggested. I suspect largely because the respondents were busy enough with their work in the hospital no one wished to change or amend the discussion agenda, but the opportunity for input was given again to participants at the start of our meetings.

All the group sessions were taped and transcribed with a symbol for each participant in order to anonymise the data. The physiotherapists and nurses agreed to look at the transcripts later, but I received no comments apart from positive verbal feedback after the groups. A formal presentation of study findings in general was made to the social work team due to the focus of the study and the part they played as gatekeepers. That feedback meeting was taped, transcribed, and used as additional data.

The discussions within the focus groups were certainly all lively, with animated debate and virtually every staff member involved contributing something. The absence of line managers at these meetings, apart from the social workers feedback session, probably assisted in the successful flow of the discussions, it was also helpful to have a mix of senior and more junior staff, the former able to pinpoint changes to working practices over the years they have practised.

5.3.3 Additional forms of data collection

From the outset other data has also been collected as described above, in the form of field notes of observations of meetings held with social workers, and visits to hospital wards and care homes in negotiating entry and in preparation for

interviews. Weekly morning visits over the first year followed by less frequent visits in the second year, yielded rich opportunities for ethnographic participant observation of social workers operating from their office base. Furthermore there were limited opportunities to discuss events for the service users with whom they were involved. Particular attention has been paid to recording common issues for the group around hospital discharge and the machinations of multi-disciplinary teamwork. Clearly one's own background in social work brings a certain perspective to bear in mind, noting comparison of changes to practice and administrative duties that have occurred since 2003, for instance.

Following the initial data analysis, and with the main themes from the data organised, I also arranged feedback sessions with the service user and carer organisations with whom I had consulted originally about the basic ideas for the research. After a presentation to the user organisation, a sub-group was keen to meet with me to further explore the issues I had outlined and their comments were used as additional data to contribute to the study, with their permission. Unfortunately, the carers' organisation, whilst confirming the study findings from their own experience of hospital discharges in that area, did not give me permission to use their detailed feedback.

5.3.4 Challenges to data collection

It took six months to get all the various NHS approvals and permissions that meant that I was already falling behind my target dates for completion of data generation. Inevitably this was just the beginning and there were other problematic issues which took a further five months to resolve, as I will outline below.

Gate keeping issues

With the onset of Delayed Discharges legislation in January 2004, and with it the possibility of local authorities being fined for older people waiting for services on wards once 'clinically fit', hospital social workers took on responsibility for the majority of care management for older patients in hospital. The community teams had previously undertaken this work. The hospital social workers were a group of staff I did not know particularly well. Moreover the Social Services Department reorganised in April that year and in spite of repeated requests the earliest I could meet with the team who would be gatekeepers to the sample was mid July. At that initial meeting to ask for names of older people to contact to take part in study, almost half the team were absent due to sickness or holidays.

To quote from my research diary:

'This meeting left me so dispirited and wishing I had persisted in trying to get together with social work team earlier ... The only keen person was XXX but she was a specialist social worker...' (i.e. not involved in care management). (Research diary [RD] 19. 7.04)

It was therefore not surprising that no names were forwarded to me during the summer and so I asked to meet with them again in September 2004.

The intervening summer months were therefore usefully spent preparing for data collection. For instance, equipment was assembled, and visits were made to care of the elderly wards to introduce myself, explain the study, and to check out if rooms were available for 'mobile' service users agreeing to participate.

Access to sample

Both staff turnover, particularly of agency social workers, and sickness were issues for the hospital team. The agency workers were as keen to take part in the project as permanent team members, but the priority for them was mastering a new job. Furthermore continuity was not always maintained and cases tended to be closed quickly, making it difficult to obtain follow up details on carers and further moves of placement. By September 2004, just three months into the fieldwork, four social workers, out of a team of twelve had left, and been replaced by new or other agency staff. However following the second meeting I wrote:

'Many more of them now, morale a bit better and ... agreed I would come in on a Tuesday morning (each week) to see if any possible patients to interview.' (R.D. 27.9.04)

By then it had become clear that the pressure of workloads on the social work team were such that I would need to go to them regularly in person if I was going to be able to access a sample of service users and fieldwork was ever going to start. In hindsight these visits to the hospital social workers' office were positive, both for the project, and as a way of enabling the social workers to get to know me better, and feel confident that I would treat the service users they had referred 'properly'. By November 2004 I received the first name of a potential study participant from a social worker.

For the gatekeepers, social workers who were already under considerable pressures, the presence of the researcher can be felt at least as additional burden

to cope with and at most as a threat. This was never actually verbalised to me however; social workers were always pleasant and welcoming. For the first few weeks I had deliberately positioned myself in the corner of the busiest room in the office building in order to remind them of the study, to approach them and be seen by the most social workers for the purpose of picking up names of potential study participants. Unfortunately a social worker did not share this perspective, as I recorded in my diary:

“ First of all I felt she thought it was too stressful to have me there at all – she said no room for me in her office, could I go to the next door one where most of the desks empty!” (R.D.2.11.04)

I should have perhaps explained my role again to her but there are no easy solutions when the gatekeepers appear too busy to listen to or speak with an outsider

As can also be seen from the figures in Table 5.5 above, a proportion of the user group died, even before initial contact could even be made. This is clearly one of the difficulties inherent in a study involving frail people who have been admitted to hospital and is not unique to this project; indeed concern for high mortality rates of new nursing home residents is a matter for debate in itself (Nay, 1995).

5.3.5 Withdrawal of potential service user and carer participants

Another challenge to data collection was the withdrawal of three potentially interested service user and carer participants on reading information and consent forms posted in advance. The formality of the (former) COREC recommended information sheet in use at that time, seemed to have so perturbed these service users, “I thought you just wanted a chat”, that they declined even a visit to explain what was involved. As a consequence material was not subsequently posted out to carer participants without prior face-to-face introduction and explanation unless specifically requested by individuals. I also designed a user-friendlier one-page introductory sheet outlining the basic principles of the study and the role of participants (Appendix 7), which seemed to be well received. As far as it is possible to tell there were no further withdrawals as a result of seeing the initial information produced.

5.3.6 Modification of study design

1. Location of service user participants

As indicated in the inclusion criteria, the original intention of the study was to interview service users in hospital prior to their discharge. Whilst awaiting ethical approval for the study, the Delayed Discharges Act (Great Britain, 2003.op.cit) came into force and began to impact upon the length of time older people were waiting on the wards to leave. Already care managers were reporting that they were last in a chain of professionals to be asked to assess the needs of older people, and they were also finding it hard to respond quickly to every referral given the sheer volume of work. All this meant that there was very little time left to interview service users for the study before they left hospital.

In our initial meetings about the study, social workers had expressed concern that older people were being assessed by: clinicians, nursing staff - including discharge liaison personnel, therapists etc so would not yet one more professional i.e. a researcher, be potentially overwhelming? In fact, I interviewed one older service user in hospital, who had been waiting three months on a ward for various reasons. She had her own room, but even so lack of privacy was apparent. Three sets of non-urgent interruptions occurred, including a doctor who determinedly tried to usher in two visitors who were more than happy to let us conclude the interview, in agreement with the service user participant. Hence all other interviews were conducted in nursing/residential homes, apart from two in informants' own homes, and these have all went smoothly with few interruptions. Even so negotiating the routine of nursing homes is not always easy and there are emotional issues concerning people in pain, death, and institutionalisation that cannot be ignored by the researcher (Higgins, 1998).

2. Follow up interviews

The original idea of holding a follow up interview with service users and carers had to be abandoned. This was partly due to the time constraints for fieldwork completion, and also as a result of the frailty of the service user participants. Some had died since the initial interview, and others had little recall of events in their recent pasts or had made it clear that they only wished to be involved with one interview. Nevertheless as I discuss in Chapter 11, although a second interview

could have added useful data in an ideal world, I would argue that this did not have an adverse impact on achieving study aims.

3. Inclusion of service users with less complex needs

The original target group for the study was patients with complex needs, but since the introduction of the delayed discharge legislation and the subsequent reorganisation in 2004 hospital social workers no longer specifically identify these patients, and instead assess the needs of all patients who are referred and meet basic criteria. This meant that it was taking longer than expected to build up a sample of patients with complex needs, and it was therefore decided to include those with less complex needs in the sample provided they had been an in-patient and had contact with a social worker.

4. Inclusion of carers of service users with cognitive impairment

In order to both increase the sample and widen the representation to include those unable to give informed consent (e.g. people with dementia), an application to amend the study to offer interviews to the carers or relatives of service users in this situation, was submitted to the LREC. This was approved in August 2005.

5.3.7 Handling and interpretation of the data

Data gathering for the study was completed in December 2006 due to a combination of theoretical and pragmatic reasons. At this point it became clear that the service users who went into care homes or returned home were repeating issues during our discussions and no new categories were emerging. I would like to have continued arranging interviews with carers or relatives of service users with dementia, but time had run out to seek new participants for the study, as I was aware that large amounts of data were amassing and fuller analysis needed to begin. As I explained above in 5.3.6 my study design had to be quite drastically modified in that I had data from one interview with service user and carer participants. I was aware that I had not fulfilled the criteria of a hermeneutic approach that recommends a minimum of three in-depth interviews enabling participants to reflect on their experiences (Van Mannen, 2002). However I did have accounts from service user and carer participants of what happened to them before and after hospital discharge – the ‘who, when, why and how’. In other words I was able to construct a response to the research questions in 1.3. I would argue that this was an ‘empirical’ outcome using a broadly phenomenological methodology (Van Mannen, 2002).

Regarding data generated from contact with professionals, hospital social workers in particular, findings were of a richer quality, and were closer to a hermeneutic approach largely because I had formed a relationship with participants over a two-year period. The outcome of the focus group held during that time then informed my next meeting with the social workers where I presented my initial findings, checked those with the group and this was used as further data.

In order to develop an interpretation of evidence obtained from the findings, I sought guidance from a range of academic authors e.g. Quinn Patton (2002) and Van Mannen (2002). I was able to ask myself what was being conveyed to me by participants in each context; mysteries or issues that merited further investigation and what were surprises that contradicted other research studies' findings. I then used Judith Riley's guidance (1990:125) on organising the evidence for interpretation:

- Using multiple sources
- Counting instances
- Checking with informants
- Relating findings to other studies
- Using quotations

She also suggests adding quantitative data, which was not feasible for my study, and use of a second categoriser to look afresh at the way themes and categories were developed. With hindsight this could have been a helpful step not available to me. Instead I made full use of my supervisory team to sound out ideas and show how decisions were made and conclusions reached.

The following steps were taken following completion of the interviews:

Transcription

Each interview and focus group discussion was transcribed verbatim as soon as possible after they were held. Only one interview was not tape recorded due to a technical problem. One interview with a relative was of poor quality due to another difficulty with the external microphone. For these two interviews detailed notes were made afterwards and for the first situation because I was aware that the interview

could not be taped I was able to write down responses in note form including a couple of important full quotes.

Interview summaries

Following transcription, I found it useful to write one-page summaries (Riley, 1996) that have helped in locating certain features from individual transcripts.

Checking back with participants

Every participant was asked if they would like a copy of the transcript, for reasons of courtesy and to check back with them for face validity. Those who took part in the two longer interviews described above, and one other carer were the only people who wanted to look at transcripts, which I duly sent. For the former I offered to call round to discuss with them, one accepted and one asked for me to post the copy. In both these situations it was agreed that rather than give them raw verbatim typed interviews, I would summarise and make into a more coherent and readable account of the whole episode of leaving hospital and what had led up to it and the outcome. The one service user who agreed to see me seemed very happy with the material and only commented in a positive way that there were things she had forgotten. She confirmed that the content was an accurate portrayal of what had happened to her and our discussion that had included her family who by then had left the area to return to their own accommodation.

Thematic analysis

The rationale for the approach to the analysis of the data and the link with the study methodology can be found at 4.3. In order to search for themes in the data I began by printing out separate copies of interview transcripts, each in a different font. Using the interview topic guide, I started by sorting out categories and finding patterns, relationships between data bits and re-occurrences in relation to the guide as a way of grouping common data. I further searched transcripts 'manually' for categories, for example 'lack of medical information' which had been raised by some of the carer participants. I also looked for similar themes to those that had been found in comparable research studies.

To summarise initial categories were constructed from three sources:

- Responses to interview questions and research project aims
- Emergent issues raised by participants, found in more than one transcript
- Themes from other studies as reported in the literature review

Sections of speech from copy transcripts were physically cut out and categorised so that they could be grouped with similar sections from other transcripts. Examples of categorised speech for each participant were also coded and entered onto a matrix for ease of visual checking back and forth for comparison during analysis and writing up. Finally categories were grouped into related areas and assigned thematic labels which made most sense in terms of responding to the project aims of service users' experiences of their discharge, the operation of social work and the effects of delayed discharge legislation upon users, carers and staff. The full list of 60 categories and six sub-themes can be found in Appendix 10.

Illustrative case examples

Chapter 4 includes a discussion of the case study approach, methods and rationale as applied to the presentation of illustrative case examples in the study. In Chapter 6 there is an explanation of the selection of cases and one illustrative case example is presented, the remaining three can be found in Appendix 2. The material in the case examples and data presentation chapters 7-9 is anonymised to protect the identities of all participants as was agreed with them.

5.4 Conclusion

The first part of this chapter sketches the micro-policy background for health and social care at the time fieldwork was conducted and then focuses on the process and progress of data generation, which took place in that locality. Given the historically low-spending by the local authority on its older population, it is perhaps not surprising that while the centrally funded study hospital has performed well according to government measures, and has achieved foundation trust status, adult social care for older people has been less favourably viewed by inspectors who dropped its assessment of performance in 2007-8 to the one star category. Hospital discharge was even singled out as an area requiring some attention in 2001, including inter-professional relationships and the number of so called delayed discharges prior to 2004, when the legislation to combat the latter nationally, came into force. However social services management would claim that hard work has been directed at reducing the numbers of delayed transfers of care and to prepare for the Single Assessment Process, amongst other national initiatives many of which were detailed in Chapter 2. The next four chapters are concerned with data analysis and presentation. Collectively they will give a snapshot of the human cost

and benefits of national and local social policy developments for older people, their families and the staff involved in hospital discharge.

6 Case example

6.1 Introduction

As explained in Chapter 4 where I have discussed the case study method in relation to the case examples selected in the thesis, the illustrative case example represented here - in addition to its three counterparts in Appendix 2 - is intended to provide context and detail at the level of an individual who left hospital. Some examples of where past authors have employed a similar strategy were also discussed in the literature review (e.g. Huby et al, 2004; Phillips and Waterson, 2002). Furthermore thematic analysis, which comprises the major part of the data presentation as in Chapters 7-9, may give the impression of fragmented data, which can distort or detract from the whole experience that participants had, i.e. before, during and after their hospital discharge. This was particularly important in this research in which recall and knowledge of certain aspects of the process varied from one person to another. More crucially the aim of the case examples I have selected, is to give a greater sense of the whole person and the interviews conducted, including service user and carer participants' backgrounds, some personal characteristics and home environment.

6.1.1 Selection of cases

As described above I turned to the work of Robert Stake for guidance on rationale for which participants to select for case example analysis. His advice appears to be a combination of the theoretical and the pragmatic, that is 'information rich' or the most accessible situations and from which most can be learned:

'When we have the opportunity to choose the case, it is often more useful to pick the one most likely to enhance our understanding than to pick the most typical. In fact highly atypical cases can sometimes contribute to our understanding of other cases.' (Stake, 1995:134)

The stories of the service users and carers who feature in the accounts are organised under headings from the thematic chapters, but in a slightly different chronology which made more sense in terms of coherent presentation.

Below, the first illustrative case example (and the second case example in Appendix 2) are both joint interviews with family members also taking part; one in which the older service user returns home and in the other the service user was discharged to

a care home. The first case example on Teresa that follows includes the perceptions of family members who have lived abroad for some years and hence it is atypical but a view of health and social care from the outside. The third case example is of a carer from group B i.e. whose relatives were discharged from hospital but excluded from the study themselves due to cognitive impairment. The fourth case example presented is with an older service user who moved to a care home from hospital. Case examples 2 to 4 can be found in Appendix 2.

As agreed with all study participants, the data in all the case examples is pseudonymised to protect their identities.

6.2 Case example 1: Teresa (U14), Gill & Malcolm, (C09&10)

6.2.1 Background

This account is based on information from a taped interview with Teresa (U14), her daughter Gill (C09) and son in law, Malcolm (C10), held in her home nearly 6 weeks after her discharge from X acute general hospital. It focuses on the family's experience of Teresa's hospital stay, the plans for her to come home and the services now in place. Teresa's name for potential inclusion in the study had been forwarded from the hospital social worker and I spoke to Teresa on the telephone to arrange a home visit. She lives in a four bed-roomed semi detached property that she owns, in a suburban district of the town. Our discussions were held in Teresa's large living room which had all the evidence of someone discharged from hospital on a care package, the items of equipment and papers that can almost transform a homely environment into one adapted for 'care' or, to look at it positively, to enable independence to continue.

Teresa has a close knit family: one daughter lives nearby with a family of her own, and the other, Gill, with her partner Malcolm, live abroad, but they travelled to England when Teresa was taken so ill. They visited her in hospital daily and stayed with her post-discharge. They joined in this interview, which was held a few days before they flew back to their own home. Teresa herself was in her 70's, a thin wiry lady who at that time had difficulty getting out of a chair and was unable to walk far. She gave the impression of someone who had been used to being independent, and an articulate intellectual person, but whose speech was impaired by the dense stroke. It was therefore very useful to have family members present at the interview,

to clarify points that Teresa was trying to get across and to talk about their own experiences of the discharge process as closest relatives. Only occasionally during the interview was there a danger of these more confident people taking over and not allowing Teresa to speak for herself, but I think we were all aware of falling into such a trap and I saw an important role for myself in keeping the interaction focused. These three participants presented with strong personalities and did not always agree with each other. Gill and Malcolm are in their 30's, the latter not being British, but he used to live in the UK, he and Gill having lived abroad for many years.

Towards the end of the session Teresa's home carers arrived early and she had to leave the room for 15 minutes. This was a chance for Gill and Malcolm to raise topics of concern to them. I realised that this was an emotionally charged time for them, having seen Teresa so ill and then leaving hospital far from the independent person she had been but knowing that they could only remain with her for a few weeks. They both explained how difficult they found NHS and social care provision to comprehend. I was also able to call back some weeks later after they had returned home to verify the transcript with Teresa which gave her the opportunity to reflect upon that meeting and on what had happened to her, and to correct or add or update points.

6.2.2 The experience of loss

Prior to her admission Teresa said that she had been living successfully alone, without any support services. Although she did have some minor health problems to cope with, she was a keen gardener and a very active member of her community. She was involved in the running of a major voluntary organisation nationally, to the extent that the day she suffered a stroke and was rushed into hospital, she had been in the middle of organising a conference for 200 delegates to be held in X city about 250 miles away. Other than this information, little else was learned about Teresa's background, her origins or marital or employment history for example. I felt that neither Teresa nor her family particularly wanted to divulge private matters not directly relevant to the research.

Teresa's assessment of the hospital care she received was that while the basic care was good, staff on the stroke ward did not appear to her to have been trained in listening and communicating with stroke patients. This was of particular significance as Teresa was dysphasic. Another difficulty for her was having to wait a

considerable time on the ward to be taken to the WC, which she believes has led to her being left with constipation now she is home. Gill concurred with this view and also pointed out that the nurses were always very busy, much of the time with serving meals.

6.2.3 Decision-making, information and choice

For daughter Gill and her partner Malcolm gaining information about Teresa's condition was a recurring issue, "They didn't tell us anything, they didn't tell YOU anything unless you particularly asked". Gill gave an instance of when they were most upset one day to find Teresa with an oxygen mask, and the nurses were very matter of fact about this, downplaying it's significance. The couple talked about how hard it is to know who you can approach for feedback on a bustling ward. Malcolm explained that they were given little idea of the nature of Teresa's condition and its prognosis or any general information about strokes. There were leaflets on the illness but as they were walking around as anxious visitors to Teresa, "like stunned mullets", they did not notice the leaflet racks and the staff were too busy, apparently, to draw their attention to them. For Teresa's part she told us that, "nobody told me a thing but I didn't care," I thought that the different attitudes towards information here was interesting, and the bearing that the illness itself may have upon it as explored by Teresa's son in law in the rest of this extract:

SF: Why do you think that was?

Teresa: I didn't care about anything – coming out or staying in. Confidence was quite important

Gill: In what?

Teresa: I just let things ride over me... I just didn't care

Malcolm: Again that was a condition of the stroke and you were probably quite lost?

Teresa: Yes

Other points of contention for Gill and Malcolm included not realising they could bring food in for Teresa, after she had lost 10lbs in weight in a few weeks; they were given a large bag of dirty laundry accumulated over many days to take home and wash; and not being advised on appropriate clothing to take to the ward for Teresa.

Planning the return home

Both Teresa and her family described a helpful multidisciplinary meeting convened on the ward to plan for her discharge. A target date of five weeks in advance was set, with the aim that Teresa would be ready to go and services in place from three

to five weeks. During that period three home visits were arranged for Teresa. The first brief one was to assess for any equipment/alterations that might be necessary, then an afternoon visit, and the final one was an overnight stay with a carer coming in to assist her.

Prior to the planning meeting, Gill outlined a chat that she had with the hospital social worker and her mother, which had been “distressing” for them both, as they had not realised that the staff initially assessed Teresa as requiring a place in a care home. The social worker therefore started to explain the financing for this in a seemingly informal way, which had come as a “complete shock” to Teresa and Gill. However as Teresa and her family were in no doubt that she must return to her own home, the chat prepared them, they explained, for arguing the case at the next proper meeting, and perhaps focussed Teresa’s determination on regaining at least some of her independence.

6.2.4 Adjustment and transition

Positively speaking, the family were delighted that the basis of the care package and all the equipment, including an intercom for the front door, were operational for Teresa’s homecoming. The actual discharge went according to plan, with no issues around its timing and Teresa was very happy to be back in her house.

However two areas caused Teresa and her family concern. Firstly the scheduled calls by care staff needed tuning, as Teresa could not be left up to 13 hours without using the toilet, so an evening call was needed. After two weeks it emerged that assistance with bathing had not been arranged. The other area concerned health issues, and there were problems in tracing the agency and person responsible. The continence assessment undertaken in hospital was no longer relevant and the pads supplied were unsuitable, so Teresa and her family needed to find out how to go about amending this and where pads would come from in the future. Furthermore how would Teresa replace her medication once it had run out and on a regular basis? In the end it was care staff and the GP’s receptionist who came to the rescue with the answers and remedies to these questions but all the above had taken a great deal of the family’s time, energy and persistence in following the trail to the right person.

Adjusting to a new life

Before her stroke Teresa had been used to caring for herself, and she was not always certain why a care worker had arrived, to prepare a meal for example, and she had sent them away once. Gill commented that Teresa sometimes needed to go to the toilet just after care staff had left, and that she herself had assisted her with this. Gill therefore wondered whether Teresa had become used to 24-hour care in hospital.

Gill and Malcolm also considered whether their presence had affected the situation in that perhaps Teresa would have had more follow up from hospital and attention post discharge had she been on her own rather than having to wait six weeks for a review of services. Furthermore they felt that once they returned to their own home, Teresa's relationship to the home carers would be able to develop.

Teresa's post-discharge difficulties were remedied eventually after Malcolm and Gill had made great efforts to find the identity of the social worker co-ordinating the care package and then they had to argue that these matters could not wait six weeks, the normal period for review. Apparently a misunderstanding had arisen due to a standard letter informing Teresa that she was being 'transferred to a reviewing officer' had been sent prematurely as the hospital social worker had intended staying involved for longer. Summing up overall views of the care package offered Teresa put it neatly herself: "Nothing wrong with social services, it's the implementation "

For Teresa her speech and her general functioning steadily improved once home. While this was appreciated, everyone did wonder whether some further physiotherapy following discharge would have benefited her. It was noted that back in her own surroundings, Teresa and the staff assisting her manoeuvring around in the way that suited them all, rather than perhaps what was considered best practice, dispensing with the 'banana board' for transfers to her wheelchair for instance.

6.2.5 Relationships

We did touch briefly on emotional support or the chance for Teresa or any of the family to talk over what has happened to them following her stroke, with a trained professional. This has apparently not been offered, but they are quite clear that

none of them would have wanted it either, and that Teresa has always been a “private person”.

For Gill and Malcolm, the problems of communication both within departments and between the organisations and themselves have been hard to negotiate, as Malcolm put it:

“When I said: who do I talk to about such & such, the response so often has been – ‘ah, look, great system, so well designed, but quite often we don’t talk to each other!’”

Everyone agreed that this is an inherent malaise of large institutions not confined to the NHS or local authorities.

6.2.6 Summing up

In conclusion, during our conversations I found Teresa remarkably cheerful and resolute to make the best of her life post-stroke. As with many new situations there are challenges to be faced. One such challenge for Teresa was having to go to bed at nine pm to fit in with the care agency’s schedule, but she accepts this is a compromise worth making to be able to live in her own house again.

To finish on a positive note, son-in-law Malcolm pointed out that they can only be grateful that Teresa’s care package was set up and running from the moment of her discharge from hospital, and he doubts whether such a subsidised support service would be available anywhere else, including the country where he and Gill reside!

Addendum

I visited Teresa having sent her the transcript summary and with her prior agreement. She read it and approved contents as an accurate representation of the interview and her views on discharge from hospital. Since the initial meeting:

- Ramp for wheelchair in situ
- Speech therapy and physiotherapy now provided
- Teresa has had one fall out of her chair but was able to summon assistance via alarm call system. She has been left with some bruising
- A satisfaction questionnaire for the acute Trust was completed, but Teresa said they decided to be “diplomatic”, and wrote only of the problem of “staff shortages” in terms of the negative aspects of her experiences.

- Teresa explained that although she is now glad about the outcome, when in hospital she had thought to herself that she ought to go into a care home post discharge, but had not liked to say this at the time to her family or any professional there.

Reflections on the interview

The participants involved in the interview told me that they found it useful to impart the detail of their experiences in spite of parts of our discussion being upsetting. I think it might have been helpful on various levels. Firstly, I agreed to pass on aspects of our discussion such as Teresa's laundry accumulating and lack of information to the hospital complaints officer. Secondly I believe that Teresa and her family were genuinely supportive of the research and pleased that someone was taking an interest in their situation. Finally, exploring the events of the previous weeks in detail, as they were able to do, may have been helpful to them in itself. I was given that impression, but would not want to claim a therapeutic effect or to minimise the distress felt by participants re-living a difficult story with an uncertain ending.

6.3 Conclusion

The illustrative case example presented here has given descriptive context at an individual level before looking at the themes from the data analysed, in the next chapters 7-9. It gives an account of one service user's and two relatives' experiences of the discharge process and introduces the themes of loss, transition, decision making and relationships that are further developed with regard to study participants in the following three chapters. The organisation of the data around these study themes is explained in 7.1. Three further case examples can be found in Appendix 2; it was not possible to include them all in the body of the thesis.

7 The themes of loss and transition in the study findings

7.1 Thematic data presentation

7.1.1 Introduction

The chapter starts by giving some background information to introduce the presentation and analysis of interview and focus group findings. These are organised into the themes that are the subjects of Chapters 7-9. Themes of loss and transition are explored from 7.2 onwards.

7.1.2 Study themes

As stated in the discussion on methodology in Chapter 4, the study from my perspective was exploratory with the expectation of raising issues pertinent to service user participants leaving hospital and their families. The interviews were structured with the principal objective of addressing the project aims of 1.3 and gave participants the opportunity to express opinions of services and to tell the story of their experiences if they so wished. The material chosen from the data for this and the following two chapters is therefore selective and not necessarily representative, which applies to most qualitative research (Wolcott, 2001). In examining instances of practice that impressed users and impressed them positively or negatively - particularly if previous research has reached similar conclusions - lies the opportunity to reflect on our interaction as practitioners with service users. It may further shape what we are about to do and have a bearing upon social policy, these matters being the subject of Chapters 10 and 11.

7.1.3 Organisation of interview data

Section 7.2, and the two chapters that follow, deal with presenting and analysing the data. The approach of thematic analysis (please refer back to 4.3.2) was just one of many ways of describing and organising findings and I could for example have adhered to chronological themes through a 'patient journey'. But issues concerning 'loss', 'adjustment' and 'relationships' occurred throughout the patient's experience - of admission, through illness and treatment to discharge and outcome. Clearly there is overlap between categories as they are closely related - 'loss' and 'adjustment' for example can be viewed as part of the same process and hence they occupy this single chapter.

I also found that the headings of loss, transition, choice and decision-making are common themes in social work textbooks on older people (e.g. Lymbery, 2005) and are considered key areas for the practitioner to consider. Nevertheless as Lymbery points out it is important not to expect or look for negative experiences during interaction with older people and to view them as always the victims of unhappy circumstances. In the next chapter for example the opposite of loss is looked at where some of the service user participants had benefited in social terms from their hospital admission and discharge, that is not purely from treatment of their physical illnesses. Furthermore social workers in the past were criticised for over-emphasising loss with disabled service users to the detriment of looking at their financial and practical needs (Ellis, 1993:12).

In order to satisfy the research aims in 1.3 and to impose a structure on the themes arising from the data, the following three main areas that can encompass all of the above categories made sense:

- Loss and Transition
- Decision making
- Relationships

The first two thematic areas and corresponding Chapters 7 and 8 relate to the intent to look at the perspectives of service users and carers on their hospital discharge and connections to social work activity. The third set of themes around relationships covers views of users, carers, health professionals and social workers on the practice of care management as it was termed, and interagency working in hospital discharge. The third project aim to assess the effect of delayed discharges legislation is explicitly addressed later in Chapter 9. However the findings presented in Chapters 7 and 8 on experiences of the discharge process are in a post-reimbursement context.

7.1.4 Organisation of focus group data

In Chapter 4 the rationale for conducting focus group discussions (4.3.2.) was discussed. The written material from focus group sessions was analysed thematically in the same way as for individual interview transcripts as described in 5.3.7. Findings most relevant to the study's aims in 1.3 of exploring the perspectives on social workers relationships to service users, carers and other disciplines in the context of the discharge process are organised under the following headings:

- Constraints upon professional endeavour
- Inter-professional working
- Older patients' involvement and decision making

The full list of 27 categories comprising these themes can be found in Appendix 10.

The reader will notice quotes and references from the staff data where particularly relevant in Chapters 7 and 8 and where their contribution can further assist in the exploration of users and carer's themes. In the third section of Chapter 9 the themes from staff data above provide the framework for organisation of that data on 'relationships'. Following a search for crosscutting themes the findings generated from the two main types of data of most relevance to the thesis topics are then compared. Appendix 9 presents these crosscutting themes and common issues are looked at as tensions from the social work perspective in Chapter 10.

In general, the data found also need to be set in the context, which generated them, the hierarchical structure of an acute hospital (McLeod and Bywaters, 2000). These factors are pertinent in consideration of the themes that have emerged from the data particularly those relating to relationships with professionals. Further interpretation of how these issues are dealt with in the literature and implications for future practice are discussed in Chapter 10, following the last of the themes chapters.

7.2 Themes of loss and transition

7.2.1 Introduction

The rest of this chapter seeks to begin addressing the research aims in 1.3 by focusing on the experiences of carers and the service users who were admitted and discharged from the study hospital. It starts with data presentation and analysis of pre-admission factors and loss of former life and independence as reported by some of the service user and carer participants. Section 7.2 looks at loss of home, the mixed feelings of carers on change, separation of partners and bereavement. Hospital admission and discharge in the study context are also about the physical transition from home to institution, and from stages of assessment in the emergency department to inpatient treatment and finally preparation for discharge or

rehabilitation. These critical points, and how service users and their families adjusted, re-adjusted and coped with the accompanying psychosocial implications, will be covered. The chapter then ends on a more positive note, with a few gains that seem to have been experienced by some older users discharged from hospital.

Eleven of the service user participants spoke to me in a striking way about one aspect or more of the loss that they had endured. Six of the remaining eight (four males and two females) had objectively suffered a loss to my knowledge but did not refer to it, and two service users left hospital after short stays with less complex needs than the majority. Nationally, more than half of new admissions to care homes were from hospitals and most of these older people have endured personal loss of some kind (OFT, 2005:2). In fact three of the 19 service users had experienced the recent death of a spouse.

7.2.2 Pre-admission factors

The events that precipitated the actual hospital admission, which have been seen as relevant to the discharge process by some commentators (e.g. Godfrey, and Moore, 1996), are the start of the journey as a patient and were a useful place to begin engaging interviewees following our introductory conversations. Users were keen on the whole to describe what happened to them prior to going into hospital. Such circumstances largely fell within three main groupings in the data:

1. Sudden onset of a major illness or trauma for those who described themselves as mainly active or healthy,
2. History of poor health culminating in an acute episode
3. A gradual deterioration of ill health, often involving previous admissions to hospital.

The crucial point for the study was that for the majority of participants their hospital admission resulted in deterioration in the level of independence for them.

In order to show how active the majority of the service user participants had been and some were continuing to be, at the point of the interview, I listed some of their personal contributions as described to me in Table 7.1 below:

Table 7.1 User participants' reported interests prior to hospital admission and following discharge 2004-6

Participant	Activity	Continued post-discharge
U02	Shopping, cooking and cleaning	No
U04	Church worship and voluntary work	Only able to attend church at time of interview
U05	Playing with grandchildren and driving	No, deceased
U06	Shopping and cooking	Yes
U07	Volunteer at a charity shop	No
U09	Ballroom dancing	No
U10	Admin work at a local charity	No
U11	Carer for spouse	No + wife deceased
U13	Photography and electronics	Still interested in electronics
U14	Secretary of a national charity	No
U15	Carer for spouse	Yes, with more support
U16	Carer for spouse	Yes, with more support
U17	Shopping and cooking	Yes
U19	Gardener	Yes with help/adaptations

N.B. Information not available for four service user participants

Acute episodes of ill health

Three of the 19 had fractured bones, although not the results of falls in the usual sense as focused on by the DH in the National Service Framework (DH, 2001). For two service user participants, the episode eventually resulted in a move to a care home, although a third participant who broke her arm was able to return home a few days after surgery. The first was knocked backwards by a dog and broke her hip, and the second according to her daughter Rene (C12) from Carers Group B: "(She) got up off the settee and broke her ankle, she didn't even fall off it. She just stood up and that's how she broke it, so simple..." Rene went on to describe how her Mother then had a heart attack and broke her hip in hospital, eventually being discharged to a dementia care home. However I was able to talk to Flo (U02) the other service user participant who had fallen and broken her hip, with a similar outcome to Rene's Mother. Before her hospital admission she was accustomed to an active, independent life as she indicated in the following extract:

SF: "So at home, before you went into hospital, did you go out?"

U02: I did everything for myself; I did own my shopping...I probably told you that I was staying at my daughters when I fell....It amazes me, I never thought I'd live this long and then all of a sudden everything seemed to go to

pieces. I was very ill and ended up in hospital - they were just saying that yesterday, they were standing round my bed expecting me going. But I came together again.”

Here as with some of the other service user participants I was impressed by what seemed an overriding sense of the shock of having felt close to losing one's life. It would have been interesting to know how and whether the feelings regarding the trauma changed for Flo over time. She did refer to the episode more than once during the interview, but then I had also asked her about the circumstances of her admission to hospital.

Gradual deterioration in health

Nine service users described a more gradual deterioration with repeated spells in hospital. This may relate to the findings of a systematic review (SCIE, 2006), which asserted that older people could view hospital admission and discharge as a part of life's continuum rather than critical event. Stephen (U18), for example, told me of several past hospital stays. He explained that his health problems probably stemmed from a car accident, which had happened 16 years previously. He was currently suffering from ulcerated skin on his back and legs that required treatment in hospital this time.

Two of the carers I interviewed, Elaine (C11) and Joe (C14), talked about witnessing the gradual descent into worsening dementia for their parents while Roy (C05) and Doreen (C08) spoke of general deterioration in the physical health of their Aunts (U07 and U08). Later in the chapter I describe the outcome for Elaine's Mother who never adjusted to care home life according to her daughter. A fuller account of her story can be found as a case example in Appendix 2.

7.2.3 Hospital and beyond

The bulk of this chapter focuses on service users moving out of hospital into a care home or returning home with a care package. For most of the service users who moved out of hospital into a care home, the intervention of relatives could be crucial:

‘Two examples of this [transition] are the process of discharge from hospital and admission into long-term care. Both of these events occur when people are at their most vulnerable, feeling powerless to affect their lives in a positive way, and often subjected to well-meaning but destructive guidance from family members.’ (Lymbery, 2005: 31)

The remaining service users who went back home had to cope with change whether it was to the consequences of increased physical needs and/or the provision of home care services. I did not actually ask service users how they felt about *coming into* as opposed to being in hospital and no one volunteered any information on this aspect. The joint NSF review (CSCI, CHAI, NAO, 2006) was critical of multiple moves within hospital for older patients. This was raised as an issue by one of the carers in the Group B. Rene (C12) for example talked about the effects of the moves for her Mother who she believed was deteriorating mentally as well as physically once she was in hospital: "But it was surprising she moved from ward to ward they weren't getting the full medical details properly." (C12). These medical details included giving Rene's Mother the correct drugs as she moved wards. Nevertheless Mona (U03) and Stephen (U18) who also moved around within the hospital were fulsome in their praise of all wards and all staff encountered. However we start by looking at how discharge was experienced by service users. The stage in-between, that is gaining information on and consideration of post-discharge alternatives and the decision making process are looked at separately in the next chapter.

Swift discharges from hospital

Once in hospital service users and their families were expected to quickly engage in planning for the future. Table 5.5 in Chapter 5 lists the actual destination and other characteristics of service users. Of those who went to care homes from hospital, including the service users referred to by carers in Group B (n=2), six went to the same transitional care unit in a nursing home, where Harry (U10) also moved permanently. Two other service users Eric (U05) and Mona (U03) went to permanent places in different nursing homes. Of the seven service users who went into residential care they were all at different locations, but two users Flo (U02) and Keith (U15) were given 'transitional' places and may eventually have moved again. The remaining six older service users returned home. One person, Carrie (U06), was relocated to supported housing.

Seven of the service users referred to lack of notice of discharge, or feeling rushed or a lack of choice about discharge date. For those awaiting a vacancy in a care home, such as Eric (U05) and Sid (U12), once a place is available it is understandable that the hospital wants a speedy discharge; but this can create difficulties for families who want to be supportive, such as Barbara's (C03), Sid's

(U12) and Rene's (C12) families in which everyone worked and/or had other responsibilities. Interestingly Rene's spoken opinion of social services in the interview centred on the transition from care of the sick person to preparation for discharge as did Diane (C04) in 8.3.2 above, and then the move, the last two stages happening quicker than expected as described in this extract:

SF: "Overall what was the opinion of the help you got from social services?"

C12: At first we were a bit shocked because one minute she wasn't fit enough to leave hospital, then they seemed to be rushing to get her out, everything seemed to be come so quickly... So it wasn't as quick as we thought from the time of one minute saying, 'she's fit enough to go in a home – here's some homes – look!', and we thought one day we would go and look, and then she would be in a home! [Laughs] So the information was given properly.

SF: So was that pressure coming from social services or the ward to do it quickly?

C12: I think it was a bit of both really but I think we maybe got that impression, I don't think they meant to give us that impression or that it was done deliberately."

Although the carer interviewed in both these cases appeared surprisingly tolerant of the messages conveyed by professionals and did not complain about lack of notice of discharge, Carrie (U06) and Hilda (U08), also Jessie (U04) and Annie (U17), whose relatives I did not meet, said they were upset about finding out about a move at the 'last minute'. Hilda spoke about her niece having to fetch her clothes and Carrie said the following: "It was a bit of a rush job really. I felt I hadn't time to collect my things together." (**U06**). For Jessie (U04) it was her one negative comment about her whole hospital stay:

"I didn't have much time to organise anything this end really. I went in the morning and I would have preferred having a chance to, you know, to talk to somebody at this end, a friend and who did turn up shortly after I came but I would have liked a bit more time for that aspect of it really, when I come to think of it." **U04**

Jessie's responses of which this is just an extract gave the impression of an older service user who was feeling quite vulnerable leaving hospital, and that neither she nor her support network of friends had much chance to prepare. Nevertheless 13 user participants out of 19, and 9 of the 16 carers, were satisfied with this aspect of the discharge and did not comment on a lack of consultation or notice of the event.

Anxiety re leaving the hospital ward

In the literature review I refer to study findings on older people's anxiety, heightened by the prospect and/or the actuality of leaving hospital (Kvaal and Laatke, 2003).

The difficulty Carrie's (U06) daughter Diane (C04) felt she had in leaving the 'known' world of the hospital ward to move to the rehabilitation unit is summed up by Diane:

"You know there's a big thing coming out of hospital. It was all sort of quite traumatic for her I think, when she went from the ward to XXX Unit. That was quite traumatic for her". **C04**

Zena, whose mother Flo, who I had interviewed, implied a loss of confidence for her Mother after a long hospital stay, coupled with a probable fear of the unknown in the following:

"She was very frightened and very anxious because she hadn't been out for so long and leaving that safe environment. She said to me 'why can't I stay here' even though she was on ward x, a locked ward, and there were lots of people there with dementia, but she felt safe there the staff were so nice to her." **C01**

In contrast Jessie who had only been in hospital for two weeks, returning home with some home care support, found the question about readjustment somewhat irritating and not relevant to her: "Don't know this kind of question about how do I find doing something, I just do it, and if it's to do, that's it you know, I don't really think about *how* I find it." **U04**

Six of the carer participants group of 16 (C01, 3,4,6,9/10,12) spoke about their fear that their relative would not survive the episode of ill health that had brought them to hospital. There was a sense of coming to terms with the possibility of loss and then having to move swiftly on to think about the scenario of that person being discharged not knowing how and whether they would be able to return to their former living situation. Diane (C04) for example talked about how she felt regarding her Mother:

SF: "Can you remember at what point you started thinking about her coming out of hospital?"

C04: I think, initially, we never thought she would survive, let alone be discharged...I don't really think we could think that far ahead initially, we thought it was serious, that we were going to lose her, and I think it was probably only when she started to mobilise that we felt there was light at the end of the tunnel."

Here is an example of the mismatch between family expectations and not anticipating, knowing about or keeping pace with advances in medical science and changes in the patient's status and situation from acute to chronically ill and readiness for discharge.

Re-admission to hospital

Barbara's (CO3) father Eric (U05) moved from hospital to nursing home, but because his health deteriorated he had several re-admissions to hospital, which she believed had a detrimental effect on his wellbeing. This is a frequent occurrence for older people, which was criticised by the joint NSF review team (CSCI, CHAI, NAO, 2006).

SF: "Is there anything else we haven't covered that you would like to add?"

C03: Not really...It was such a long stay in hospital. And all that backwards and forwards - they were sending him out too quickly, before he was ready and that was really traumatic for him. But obviously they thought he was well enough to go back as they had done what they could. But it just started again and he was back in again."

Barbara also indicates above something of the stress endured by the family who visited and watched Eric continually having to re-adjust to changed surroundings while his health was deteriorating. An occupational therapist (**OT**) was one of the few professionals to comment on the effects of multiple moves for older people and their families as in this assessment of one man's situation:

OT B: "We have got transitional care unit now for people to go to but its another move. Like we had a case conference on this man who wanted to go home, but he agreed to go to transitional care and now they've got the same problem with him, he doesn't want to move to a care home, whereas if he only had the one move...I mean its great for social services and the hospital but for him to have to go through it all again and its backfired as now he's adamant that he wants to go back home."

One is nevertheless left considering how many older people are able to express their views on moving locations and how many are supported in their self-determination not to comply. Further views of the use of transitional care are explored in section 7.6 below.

7.2.4 Leaving hospital and loss experienced by service user participants

Loss of former life-style and independence

As described in 7.2.2 above, participants described loss of independence recounting what they were able to do before the illness that took them into hospital. Nevertheless 'interdependence', as opposed to 'dependence', as a concept of a continuum has gained credence (Counsel and Care, 2005, for example) in recognition that everyone is dependent upon another human being to a certain extent. With an interdependent perspective, frail or ill people might be seen as experiencing change rather than loss. In this case a relative portrays the vital role his mother in law, one of the case example participants, played in a national voluntary organisation prior to her hospital admission:

C10: "But you were very active before the stroke, constantly running around, spending 10 hours a day in the garden, running errands for people, you worked for X [organisation] for 20 odd years, 32 I beg your pardon, right up until the day of the stroke the house was full of clerical forms ...

U14: Well I was running a conference for 200 people."

Teresa's (U14) background and the outcomes for her were looked at more fully in the case example of Chapter 6. Post discharge Teresa was unable to speak or write as clearly and as easily as she had been able to before and because of mobility difficulties, found herself being in a position of receiving help rather than giving it to others. Some weeks later when I saw her again there had certainly been improvements to her speech but it was doubtful if or how she would be able to resume her previous active roles in life. Teresa was one of the majority of service users whose loss from illness was reportedly permanent.

For three of the men, but none of the women, no longer being able to drive was specifically mentioned as the following dialogue illustrates:

U10: "I gave my lovely car away to my son.

C06: That was the biggest thing to lose your car."

In this case of a couple living in a village where only the husband drove, the loss of that function was not just about loss of independence for the male but also brought about a new set of practical difficulties for them both.

A daughter, Barbara (C03) talked about the important role her Father Eric (U05) played in the family, regarding his grandchildren, prior to suffering a severe stroke:

“The children used to go but they’d get upset...it was upsetting ‘cos he used to drive them around and he was always good fun, but towards the end he was just so tired of it all.” **C03**

Eric’s family were finding it hard to visit him confined to a bed in the nursing home and I wondered how aware he was of any reaction that might have been shown to his state of health and changed role. Eric had actually died by the time the interview with his daughter took place.

Indicating something of the balance between risk and leading a satisfying life, Sam (U13) conveyed at the very end of the interview some of his feelings about his new situation in a care home, where he had lost the ability to be able to go out as and when he pleased.

U13: “I don’t like it here of course.

SF: No? What don’t you like?

U13: I’m all cooped up.

SF: Can you not get out and about at all?

U13: Well I can if I ignore them, I wasn’t allowed out at first. But I’ve got them round to my way of thinking. I’ve got the whip out [laughs] I’ve always been my own man you see.”

This extract also illustrates the difficulty both service users and their paid carers have in exercising their wishes to take continuing responsibility for their own lives following a move to a care home. Another service user participant, almost six weeks after leaving hospital, felt she would never be the same again, psychologically, rather than in terms of physical capabilities:

“Well I feel quite proud of myself for coming round so much, ‘cos I was in an awful state. Anyway that’s all gone. I must have been, you know, a bit off my head. I still feel a bit missing like but not the same person. I know I’m not the same person.” **U06**

However in the same interview Carrie explains that she was unwell for quite a while at home, and her daughter, a nurse, was expressing concern: “She said ‘Mum I think we’ll have to go into care’ she said ‘because you’re not managing’.”**U06** The

hospital experience for this service user who was not managing at home was nevertheless a mixed one. Her daughter Diane (CO4) explained that Carrie benefited from the care and attention from staff and then suffered a loss to leave that behind following discharge, which is looked at later in the chapter.

Loss of home

Losing one's home, for some the place where they had lived for 50 years or more was a highly sensitive area and it was not possible to discuss personal feelings on this with every user participant. It was a matter of judging at that point whether it would be too distressing for the person to recall how they felt about not returning home. 'Home' clearly has many meanings as a concept, including house or flat, family and associated rituals, pets, refuge from work, garden with a potting shed perhaps and other activities or hobbies possibly extending to the immediate neighbourhood. One social worker reflected upon the situation she saw older people in:

"It is a very traumatic experience for somebody who's accepting the possibility of home care or a placement at often a great age. To the hospital they are just that person in that bed - they just don't think about the lives that they've had and the contribution that they've made. Its what B said about the loss, its not just that their husband may have died but they are losing their whole life, having to go and condense their house, their life into a pokey little room, with a little furniture with them and a few photographs. Could any of us do that?" **S/W C**

The issue is also connected to the choice of options for post discharge location, detailed in the next chapter. During our conversation some of the female users, U02, U06, U07, U14, and two of the men U11 and U13, actually spoke themselves of emotions from being "disappointed" at having to give up their home to "much rather be at home" or "if only I could walk I would go home". Edith (U07) and Carrie (U06) talked about their property being sold, Carrie even referring to a fear of being "out on the streets" having to leave her home of 53 years where she had raised her children. Teresa (U14) described how she had been very distressed when the social worker had unexpectedly raised the matter of future care at home not being feasible for her: "I broke down briefly, for a few minutes. They said I couldn't go home and I was surprised wasn't I?" (U14). The nurse who conveyed to Rene (C12), what had happened when her mother had been told she was being discharged to a care home, had also said that she had been 'shocked' and 'upset'.

Similarly Fred, supported by district nurses and home care, had been living with his sister who had some health problems of her own, so the wider family were concerned about the continued impact upon her of Fred's illness. Unfortunately she did not feel able to take part in the study. Fred (U01) who had been in both hospital and in transitional care before had not imagined that he would not see his home again and said: "Ay yes it was a shock as I expected ... I expected to go home and just improve..." **U01**.

Not everyone talked about distress at *not* being able to return home. This may be because one's 'own home' was associated with a recently deceased spouse and was therefore no longer the same home. For example, Gertie's (U09) experience is described in the case example Appendix 2 and 7.11 below. Peter (U16), Keith (U15) and Len (U19) said they had all been keen to leave hospital and return to live with their partners, the first two being carers and in Keith's (U15) case to join his wife in residential care about which he was fairly matter of fact. Nevertheless while Keith had not stayed overnight in residential care he had been for short visits to his wife. Later he told me he was pleased about this experience and how the care staff treated him, although he hoped they could move on to supported housing.

7.2.5 Mixed feelings of relatives

It was not surprising that some relatives expressed mixed feelings about the person they had cared for moving from hospital into care home and the situation of those separated from their lifelong partners is looked at in 7.2.7 below. Joe (C14) explained in the following quotation he felt relief as well as sadness when his Father did not return to his care. I asked initially how his Father coped with the decision:

C14: "We said about changing his bag, so like me he asked why couldn't a nurse come in, so we explained the situation and I think he realised that things were as bad as they were and that's why he had to come into a care home.

SF: How did you feel about that?

C14: Relieved of the responsibility. I certainly couldn't have changed his bag; I would have made more mess than he would. You know I miss him, sorry he's not here, but I was cooking for us and looking after him."

Both Joe and another user participant's son Simon (C02) did not have paid employment and described the caring role becoming a significant part of their lives, which although it had become difficult for Joe, would be missed. In contrast to Joe

however, Simon (C02) whose Mother was also discharged from hospital into a care home, did not disclose his feelings about separation. Nevertheless Simon had indicated something of his emotions of shock and sadness when relating how he found out about this outcome, referred to in the end section of Chapter 9 (9.5).

Bob (U11) had also talked about the possibility of living with his daughters, the only user to mention this. Flo (U02) made reference to her daughter Zena (C01) living in a town some miles away and stated that it would be difficult for to care for her. As for Zena, she implied that she had felt guilty about Flo's move to a care home and indicated that she had wrestled with the idea of becoming a full time carer of her mother:

"They were telling me things that I had brushed to one side. My mother's care needs, but I had to face up to it because my mother has lived for such a long time we are older than usual, to be taking that on..., my husband is in his 70's which does make a difference when it comes to caring for a parent as old as my mother, and I had to give her the best you see."

C01

Diane (C04) too, a nurse by profession, said she had felt as if she should look after her mother: "I must admit I felt like wrapping her up and just bringing her home"

C04. In both the above extracts these carers were weighing up not only their own situations with their parents needs, but were also clearly trying to consider what would be in everyone's best interests. For Zena (C01) above, she indicated that the "best" care for her mother meant professional care.

7.2.6 Adjustment and the move to a care home

Transitional care/rehabilitation

Over half of those service user participants who left hospital for a care home went to temporary or transitional places pending a more permanent destination or to try out care home life as happened to Elaine's (C11) Mother as explained in her case example in Appendix 2. In the situation of Flo (U02), the home housing the transitional unit did not have a permanent vacancy at the point of her discharge. I asked her daughter Zena (C01) for her opinion of the moves:

"I don't think it's very good. I know that its nobody's fault that she's had all these changes but I hope she can stay here I just don't think its fair to keep moving an elderly person about like that, these things have to be considered." **C01**

Zena told me that Flo had already been in four different hospitals prior to the last one from where she was discharged to transitional care. Similarly Joe (C14) spoke about the effects upon his Father of moving from hospital to a transitional care unit to a different room in the same care home, although in his case his memory loss could have added to disorientation. Even so, as demonstrated in the extract below, his Father had an awareness of the chain of events that began with his hospital admission:

“When he first moved in he was in transitional care on the top floor to see if he liked it and I liked it, but he kept saying ‘why do they keep moving me around’ even though I told him a hundred times. He’s a bit more settled now. The only thing he said to one of the nurses was if he’d have known what the outcome was going to be he wouldn’t have had the operation in the first place, he would have put up with the problems.” **C14**

As Joe points out, it was difficult for him to explain and reassure his Father and later he commented how his social worker had helped to convey complex information to this man. Carrie (U06) was one service user who went to a rehabilitation unit and then on to a new home in supported housing as I discussed with her:

SF: “So what was it like for you, those moves in a short space of time?

U06: “Well, a bit too much you know. I couldn’t cope, I felt, and then selling the house, and then coming and picking what you wanted. It all seemed, everybody else would have been off their head with it all, but I said, well I was off my head really...”

I actually asked in the physiotherapists’ (**physios**) focus group whether they ever came to hear of outcomes for older people discharged to intermediary locations:

Physio H: “It doesn’t matter what system you have in place it always doesn’t work for the odd one or two. The move causes problems or they don’t want to do it in the first place.

Physio F: We do get people who don’t want to go, but we don’t get any feedback from transitional care.”

The first part of the last comment was of concern particularly when representatives from all professionals had referred to pressure on older patients to accept offers of transitional or rehabilitation places to free up their hospital bed. In the next chapter 8.4.1, I look at how transitional care was viewed as an option and a place where users can try care home living. Out of the six users that were in a transitional care unit, four were said to be having difficulties adjusting to it or not happy. Notably,

Hilda (U08) was forthright about her opinion of the supposed opportunity to sample care home life.

Users and Carers describing their adjustment to permanent care

Adjusting to a new life at a care home was, as one might expect, reported in a different way by each of the user participants. The relatives interviewed tended to be more critical, apart from Rene (C14) who was the only one of this group whose relative actually went to a specialist dementia care home. For the four carers of service users with dementia there were added difficulties that memory loss and the need for specialist care bring:

SF: "How did she take it that she was moving in to a home?"

C12: She was a bit upset the nurse said, she went in like shock mode, but after a couple of days she settled in there...She's settled in very well, but she does have bad days like on Tuesday when the social worker XXX came..."

Nevertheless Rene (C12) said she remain concerned about the possibility of care home staff asking for her Mother to be sedated as that had happened in hospital, which she strongly felt caused further physical and psychiatric problems for her. But Rene also believed that staff were trying to avoid this and helping her Mother to adjust in her own time.

For Elaine (C11) her Mother tried transitional care in a standard nursing home and although she managed the transition from hospital to the home as she "forgot about hospital", she never really adjusted to being in a large institution. According to Elaine, her Mother moved back in the end to her own home, with a package of home care, with the support of social worker, OT and others. At the time of the interview this was working well for all concerned and is further explored in her case example in Appendix 2.

Joe's (C14) Father not only had dementia but was also partially sighted and the care home did not meet his expectations in a number of ways:

C14: "I had to remind them he was partially sighted AND explain the best way of helping him find food on the plate! I've reported it and I've had to pull them up about it .. Otherwise they look after him – the bed, teeth, everything else, you can't fault it.

SF: What does your Dad say about it?

C14: Well I spoke to the Sister and she said that Dad has only got to say something to them, but he won't. When he's complained about other things I've told him to tell them, but he never does. He says they ignore you more, but he's not like that, I'm different.

SF: Its good he's got you to speak for him. Has he told you his opinion of the home?

C14: .. the only thing that concerns me is he sits in a chair all day. I've taken him in a tape machine so he can listen to tapes, from talking newspaper etc. but when I ask him, he says what tape, he doesn't seem to have any interest in anything. He can work the machine off by heart..... When he was upstairs they used to have the TV blaring all day and there's nothing worse than having the sound on and not seeing the pictures. He's also always been introverted and kept himself to himself."

This picture of discomfort in adjusting to communal living and of older people unable to state their needs to care staff was shared by Kath (C13) as in the extract below. Her husband had dementia too and Kath was particularly worried that he understood that he was in a care home nearby and why he was there. She explained that he had not been eating well and lost weight since his hospital discharge and move. Kath was concerned that the environment was suited to his needs:

C13: "I can't say I'm impressed, he's on 2nd floor in a big room ..

SF: Has your husband said anything about not being able to talk to the others in the home?

C13: He's a reserved fellow, he wouldn't make any advances to another lady, you know. I suppose they're the same, they won't nudge him on the arm and say 'how are you doing?' For instance it was a beautiful afternoon, I went up at 2:00, curtains drawn, lights off and telly was on and no-one looking at it, one of those silly cartoon shows. They should have them by the windows looking out at the tomato plants or even the cars at the end of the street, curtains drawn and everything...

SF: I do hope your husband picks up; he's not been there long.

C13: Trouble is he doesn't know what he's adjusting to, I feel he still thinks he's coming home."

Kath highlighted here one of the major difficulties for those with dementia in general, and their families. As relatives reported, information may not be retained, the older service user may not remember even when they have visitors, and it is much harder for them to become familiar with new surroundings and to relate to a large group of

ever changing staff. It is therefore possible that these service users could feel abandoned in such situations depending on the level of cognitive impairment.

Roy (C05) also had worries about his Aunt, who did not at that time have a diagnosis of dementia. He expressed concern about her adjusting to living in a residential home and whether she had enough 'supervision'. Two other carers of participants from the user group expressed their reservations about the care and the environment at different nursing homes. Doreen (C08) talked first about her Aunt Hilda's adjustment to transitional care, echoing some of the issues found in the transition to care home life as above:

SF: "How did she take actually not being able to go home?"

C08: Well, I'm trying to think, I don't know, sometimes she talked as if when I get better I'm going home.. But I mean, she's definitely got a memory leak,

SF: What do you think of the care she is getting at XXX ?

C08: Well, I don't know, again I don't think there are enough staff because you can never find anybody when you want to... the staff are very helpful and you ask them things .. I've got nothing against foreigners, but some of them don't understand what you are talking about, you know. I will say that the actually qualified nurses, well I think there is only one on each floor, I think there is an Indian lady there, when you can actually get to her, and talk to her, she's fine, she's very helpful...It's just I suppose they are paying them the minimum wage."

Two other relatives spoke about communication difficulties with staff but using words that I found essentially more racist than in the latter extract.

Flo (U02), talked about going home when her 'legs were better' and Hilda (U08), Doreen's Aunt, was also able to speak eloquently about her experience of the move:

SF: "So was life in a care home like you expected?"

U08: Not really. I was expecting to have time to myself to do things and time when I wouldn't but its not really like that, its hard to explain, and it all sounds as if I'm very ungrateful and I'm not...

SF: Now about your discharge, is there anything that you would like to have been done differently?

U08: I would like to have come to a room of my own with a toilet that I can get to as I can't get to my toilet by myself... I'm very frightened of walking and talking... The food is thrown at you on a tray in your room – soup,

sandwiches, cake and I'm not much of a one for cake. Sandwiches are a bit dry and boring aren't they? I'm used to helping myself."

The importance of comfort and food, not only choice of what is provided and how it is served, links in with Edith's (U07) unfulfilled expectations of a cooked breakfast when she chose a particular care home.

In contrast Gertie (U09) and also Eric (U05) expressed positive views on the move to a care home, although in Eric's case he did not look very strong or full of energy, which probably affected his ability to converse but he said that the home had met his expectations: "They're doing pretty good." (U05) His daughter (C03) however had reservations about the environment meeting his needs rather than the care provided, although she did not comment on Eric's adjustment:

SF: "When he got to the Home was that how you imagined it would be?

C03: Its hard to say really.. he was just stuck in his room and to be honest he saw less going on than when he was in hospital! But we just came there in an evening once we had finished work, so he saw nobody all day. It wasn't quite the vision I'd had, but if he'd had the wheelchair he would have been able to have got out the one room.... But he was fine there, he was well looked after and everything. But there were so many different things, combinations like not being able to eat and having that peg. It was difficult for him to keep his spirits up."

It was the other way round for Harry (U10) and his wife Lydia (C06). She was more positive about the care home than he was, as from her perspective it seemed to provide some much needed support for her as a carer: "You were very upset for three days weren't you. Everything was wrong, nothing was right. A shock to your system really." **C06**

Service user participants had different experiences of their move to a care home, which they related, albeit often briefly during the interviews. It is of course possible that as our conversations took place in the care homes, that setting in itself, in addition to factors such as participants' perceptions of researcher and her approach, affected their preparedness to give honest opinions. However, Sid (U12), who had moved to the residential home recovering from heart surgery, following the death of his wife but supported by his sister in law Amy (C07), explained his feelings of awkwardness in a reluctance to mix with the other older residents who were a different generation from him:

SF: “So how do you think you are settling in here?”

U12: [shrugs shoulders and shakes head...] They look after you really well, the staff are excellent, but I don't want to come out of my room. They keep trying to get me to mix with the others. Two ladies came in to say hello yesterday. They were in there 90's!

SF: Are there any men or other folk for you to talk to?

U12: Yes, two men, but I want to have my meals in here.”

Sid's attitude to the companionship shown by fellow residents was illuminating but other service users said very little about the minutiae of adjusting to care home life. Flo (U02) and Bob (U11) gave some indication however. When I asked Flo talked about her current situation in the care home she responded:

U02: “All the girls have been very kind, and the young men as well, very good, they don't get embarrassed at seeing everything. [Laughs] I've got used to it now, it doesn't bother me, it did at first, it has to be done, I can't do it for myself.”

Here Flo hints briefly at some initial embarrassment she might have felt at young male staff performing personal care tasks. Bob (U11) also now in residential care, became quite emotional when he talked about his new life:

SF: “What about this home. What's your opinion?”

U11: Very good. They can't do enough for you. The food's lovely and as I say they, they're always on to you: 'can I do something, if you start it?' [laughs]. Sometimes they fasten my waistcoat [tearful]: 'Come on Mr X, we'll do it'.”

Formerly a long term carer of his wife who had died recently, Bob again referred to food and in his final comment seemed overwhelmed by the attention and help he was now receiving.

7.2.7 Adjusting to being back home and receiving services

Only six of the 19 service user participants returned home with a package of home care. One of those was Len, a double amputee discharged from hospital, who was extremely positive about his future at home with his wife and with an increased package of care to support them:

“There's no point in not being honest and making out you are worse than what you are. I could have said I don't know what I'm going to do for the rest

of my life. I'm hoping I can get a grant for some raised flowerbeds so I can do some gardening." **U19**

Two other service users Stephen (U18) and Peter (U16), who had gone back home, commented that they found coming out "strange at first". Stephen explained that although "it was a bit strange the first time: this time I was ready for it." (**U18**) Stephen also found that he had to get to know some new home care staff, as the assistants who had previously worked with him were reallocated on his readmission to hospital:

SF: "So is it a different agency now?"

U18: No its just council, but nothing seems to materialise but they're so rigid.

SF: In what way?

U18: In what they'll do and you never know what time they're coming, or if at all, to tell you the truth. There's a contract in the drawer. It's never the same. Take yesterday, she's supposed to be here an hour and half for my domestic and shopping. She was here less than five minutes, made me a cup of tea that was it. My daughter came later and did my shopping.

SF: Did they say why they couldn't stay longer?

U18: No, they say its up to me to ask for it. I'm going to stick to the contract in future. It's supposed to be half hour visit twice a day and like I say sometimes its five minutes both times. They mark it on sheet."

At Stephen's insistence I did look at the time sheet – he was correct in the assertion that domiciliary staff were not spending the time allocated on the contract with the service user. Similarly Teresa's (U14) family not only had concerns about the home care package, but also lack of provision of a bath, medication and the correct continence pads, her needs having changed since the hospital assessment. This was looked at more fully in her case example in Chapter 6.

The outcomes for service users returning home with a care package was also discussed in the focus groups. A physiotherapist here talked about lack of home care staff and the wider problems of recruitment, the low status of the work and how that reflects on a society. In the following the occupational therapists discussed the fitness for purpose of the home care service in general for older people, particularly regarding the nutritional and social aspects of preparing meals:

OT D: “Also you can set up a care package and then the carers don’t turn up or they only give them 10 minutes. We can identify the need but we have no control over that, and it’s not always as good as we’d like.

OT B: They can’t always get the home care, especially in certain areas.

OT A: The care isn’t like it used to be, it’s like the hospital services, very much as sticking plaster services, quick fix. Older people enjoy a proper meal but they are encouraged to get quick ready meals for the microwave oven, and how many older people can work a microwave oven?

OT D: They haven’t got time to sit around any more, you say ‘assistance with meal preparation’ and that’s a microwave meal not using fresh ingredients, they only allocate 15 minutes.”

Carrie’s (U05) family had spent some time re-furbishing her new flat for her discharge. Carrie however, was uncertain about her decision and was in a low mood following the move, somewhat to her daughter’s dismay as she (C04) explained:

“We’d worked so hard because we all have jobs to do, we’d worked so hard to try and pull it altogether. Arranging decorators and the carpet fitters being there and moving furniture, we did all that you know. And I was really hurt and realised that she wasn’t herself, but she was having to come to terms with a lot of changes. But she’s settled now, but initially I don’t think she knew how she felt really. She kept saying I don’t know what I feel, she’s sat sort of like this with her head in the hands, looking very miserable, and that wasn’t quite the reaction I’d expected. I wanted her to walk in and say ‘Oh it’s nice, it’s light and airy and I like the carpet’, because she chose it, and you know have a look round and bustle a bit, but she didn’t, she didn’t, she just noted the plant, said she hated it, and sat down and looked depressed. So that was really hard.” **C04**

The above does indicate something of the difficult position that family members can find themselves in, particularly if they have been instrumental in the decision-making. After hard work in preparing a new place for discharge, what to them may appear to make up for leaving the ‘old’ home, may not in their terms compensate their older relative for loss of the familiar.

7.2.8 Separation of partners

Three male service users were separated from their partners to be treated in hospital. Two were actually carers for their wives, one of whom had to be looked after in a care home whilst her husband was an in-patient. The other spouse had an intensive home care package to meet her needs. All were reunited with their spouses by the time of the interview and did not comment on the separation but

spoke of the importance of keeping in close contact with each other. The other service user, Len (U19) had been admitted to hospital to have a second leg amputation. I interviewed both him and his wife Nora (C15) three weeks after his return home. Nora spoke of her daily visits to keep in touch and to assist in raising of her husband's morale.

Kath (C13) however told me she was devastated by her husband's move onto a nursing home. The care home was in the same village as their house but her mobility difficulties meant that she was reliant upon taxis and others to take her to visit.

SF: "How did you feel when the social worker said that about your husband going into a care home?"

C13: Well I realised with the use of the wheelchair and a hoist that I couldn't do it as much as I wanted to. It was traumatic, very traumatic, nobody seemed sort of take it – we'd been married for 63 years, it's like losing... "

At this point Kath became quite distressed and I realised that she had not spoken about her feelings regarding the separation before, which she went on to confirm later in the interview.

7.2.9 Bereavement

As referred to with regard to attitudes towards 'home' in 7.4.2 above, three service user participants I was aware of had suffered fairly recent bereavements relevant to their situation post discharge, as they were either unable or unwilling to continue living alone. The others who were alone had lost their partners a while ago and it is not known what bearing that loss may have had upon them mentally or physically. Gertie (U09) however was open to talking about her emotions and experiences and seemed to want to talk to detail what had happened to her:

"My husband was taken ill and kept falling and I tried to pick him up. So then... I was taken to hospital and was there three weeks. Then I came home and was in the garden and tripped on a rose tree and gashed my leg. The gentleman of the house next door took me to hospital 8:00 at night and they said in hospital had I got my husband with me and of course he was here in the mortuary. The stress of it ..." **U09**

Because these service users were clearly still grieving, I did not find the discussions easy, as I was anxious not to upset them any further. A modern matron who joined

the doctors (**DR**) focus group, summed up what it can be like for older people in this situation drawing upon her own personal experience of her parents:

“A lot of them might have lost their partner of 60 odd years, which was my Dad. They had been together for 60 years and that was the catalyst wasn’t it? All of a sudden Dad’s lifelong support wasn’t there any more and with the best will in the world, daughter couldn’t fill Mother’s shoes. It’s hard, very hard.” **DR A**

7.2.10 Resignation/acceptance

The ‘loss’ evident in some of the emotions described by relatives at separation from family members after years of caring for them were explored above, from distress to ‘mixed feelings’ and relief for some respite from physical caring and worry.

Regarding older people, as discussed in the literature review, it is an issue for debate whether they appear to passively accept a situation, like suddenly needing to move into a care home (Reed and Stanley, 2000), or might in fact adopt different approaches to reconciling themselves to change (SCIE, 2006). Flo (U02) for example, eloquently described her feelings about being in a transitional care unit:

“Well I’ve just accepted it as there’s nothing else I can do, I’ve just accepted it for what it is, there’s no saying anything else is it? I don’t want to stop, I want to go home, but that’s stupid, silly but I’ll just take every day as it comes, there’s nothing else I can do about it – they’re doing their best to try and get me somewhere permanent if possible, or get me walking and then I can go home.” **U02**

Len (U19) now a double amputee and his wife Nora (C15) said little about the fundamental changes to their lifestyle that Len’s surgery had brought, apart from a brief reference to grief which seemed to be swiftly followed by a ‘re-grouping’:

SF: “I know you’ve had all this practical help but has anyone talked to you about how you felt or the emotional side of things?”

C15: No. Mind you the biggest one was when he had his first leg off, we had about five or ten minutes cry, then we pulled ourselves together.

U19: That’s it, you just have to get on with life; we’ve got a car so we can go out.”

Note that the car crops up again here as an important aid to independence for men. The stoicism expressed by this couple was also striking.

Understandably some users referred to mixed feelings about their change of environment. For example Edith (U07) spoke positively of her pleasure at the care

home being “just like a hotel”, then later in the interview she said in a sad voice that she only wanted egg and bacon for breakfast but this was rarely available. It might be hard for older people to talk to a stranger about regret or ambivalence in the relatively new care home setting, and it would have been interesting to have returned for a second interview and consideration after a few more months. Sam (U13) from being almost enthusiastic initially about his new life in a residential establishment seemed to reflect further during the interview. The following took place regarding his review meeting:

SF: “Were you able to be honest about your opinions?”

U13: Oh yes I don’t like it here, but who does? I spoke to a few that are reasonable, they have the same opinion, we wish we were back home, but we can’t. If I’d kept my home going, I couldn’t go back really, because I’m not fit to go.”

The latter point clearly links into the debate about the actual choice that older people are truly faced with that is looked at in Chapter 8. Sam was the only one of the service users who spoke of some more meaningful communication with fellow residents.

7.2.11 Some positive outcomes of hospital admission

For Gertie (U09), the period in hospital actually seemed to bring about a positive change as she did not wish to continue living alone and could not be persuaded to return, even with a package of home care: “I said that’s no good to me. I’ve got to have someone to talk to...” (U09). When I met Gertie she said she was happy at the care home. Her situation is further discussed in a Case example in Appendix 2.

Being in hospital can bring access to services not so readily available in the community, either because the circumstances of users had not come to light, or because they had no knowledge of service provision, or because in leaving hospital such older people become priority candidates for services (CSCI, 2005). The latter situation would most likely have applied to Jessie (U04), Bob (U11), Keith (U15) and Annie (U17). Jessie, Bob, and Annie all told me that they had not received social care services previously, and Keith became eligible for an increase in support. As Annie (U17) explained in an elated manner about returning to her flat post discharge:

U17: “I thought it was a bit too much at the beginning somehow... But I had a bath and had to hold on to the rails so I thought to myself ‘if nobody was there’...I’ve been ever so pleased. I had a shower this morning as the lady didn’t have much to do; she was in the room watching me. So yes it’s very good

SF: Do you think now that was the right amount of help?

U17: Yes..The second day I was home that contraption arrived, the trolley – maybe in 10 years time, I haven’t touched it and then a rest for the bath. I said I don’t want that, I stand and have a shower.. It’s been a very interesting episode”.

Here Annie has described in a few sentences a positive perspective on her hospital discharge, even if she was given equipment she did not need at the time. I must emphasise that these comments are within the context of stated wished outcomes for the service users concerned in terms of the quality of their lives following the loss of some of their health and independency.

7.3 Conclusion

In this chapter I began by looking at the organisation of data from interviews and focus groups into three main groups of themes. I have then presented some of the findings associated with the first broad area: that of loss and transition, portrayed by service users leaving hospital. In that sense it forms a response to the first of the main project aims in 1.3 to look at how older people experience their discharge, the processes and outcomes and how their needs were met. Even if social work features little in the data presentation, the experiences particularly of domiciliary and institutional care detailed here are of relevance to practice with indications of how care services and discharge itself could be improved. An important finding was that even those service users Flo (U02), Mona (U03) Carrie (U06) and Hilda (U08) who had been in hospital some weeks or months, did not complain about the length of time or talk about being keen to leave.

Only one service user, Teresa (U14) named confidence as something she had lost, with the onset of a stroke. Not knowing the participants and how they lived their past lives it is difficult to assess how far many of the other users may have felt similarly. On the whole the female service users were more likely to talk about their emotions than the males and a few of the participants in the carers group spoke about loss – in their case of their role and a changed relationship to parent or partner.

7.3.1 Summary of main points:

- The older service users referred to active lives prior to ill health and their hospital admission, which for the most part they could not fully resume. The types of loss in service users' accounts varied from loss of being in one's own home, to no longer being able to go out to shop for oneself or to lead a full life as a volunteer or as a carer. Some service users however clearly benefited from their hospital stay in gaining access to new or increased services.
- Some users described being admitted to hospital with relatively minor problems but which escalated into life-changing conditions. Others had experienced a gradual deterioration in health or a major trauma such as a stroke.
- Loss of home, independence, social contacts and close relationships were all borne by service users, with longstanding and recent bereavement a factor for some participants
- Carer participants expressed on-going concerns for their loved ones mixed with some relief for assistance and services provided. Linking in with the themes of decision making in Chapter 8, some carer participants also talked graphically about relatives nearly dying, the shock of that and the patient's recovery followed by the need for quick thinking around discharge.

Transition themes

- Many service user participants experienced moves between wards and moves from one location to another including rehabilitation and transitional care.
- Some of the user participants were reported to have been anxious about leaving the hospital ward.
- Some participants commented upon the lack of notice of their departure time or a rushed discharge. These service users said that they would have liked longer to contact friends or family and gather possessions while some of the carers wanted notice so that they could bring clothing in and accompany the older service user to their destination
- Service users seemed to experience varying levels of difficulty with their situation post discharge and some of these difficulties were reports by

relatives, particularly lack of stimulation, attention to detail and isolation in care homes, for several of the males but only one female; 'rigidly' practised homecare and some co-ordination problems regarding community care packages.

- Transitional care units were not as popular with service users, as one might suppose a halfway house type scenario, giving space to make a final decision about care homes, might be. This could have been a finding that applied to these participants only, a coincidence. Most went to one unit in a nursing home that was at the far edge of the town so not convenient for everyone, it had a higher resident to staff ratio and it did not feel much more homely than the hospital. The sheer effort and stress of the prospect of further moves as observed in a few situations could also be a factor for the new residents. From other research on support for older people re-locating (Reed, Cook, Sullivan and Burrige, 2003), it was doubtful whether much if any time is given to older people there, or at any of the other care homes, to help them adjust to the new location or to assist in deciding about a future one.
- Nevertheless service users were mostly retrospectively positive, and accepting of their current situation. They and their families appreciated physical care and how it was administered. Older service users seemed understandably keen not to criticise those responsible for their care and some merely hinted at any problems for them in the adjustment process.

7.3.2 Concluding Comments

As explained, users' backgrounds varied as to the extent that they had experienced residential or domiciliary care first hand or via visits to friends or relatives in the past. Carers and family members who were so instrumental in deciding upon choice of home as described in the next chapter seemed to have less experience of care homes. From discussions with both social workers and participants however, the hospital team did not usually give emotional support to older service users on their caseloads re-locating post discharge, other than in the way they were able to guide users and carers through the process.

At the very least the move is likely to be a permanent one as few move to other homes (CSCI, 2005). Interviewing service users and their carers about these matters was both revealing and distressing, particularly thoughts about the need to choose a new home in the space of a day or so; and to the best of my knowledge

the majority of service users did not even have a last glimpse of their former dwelling. There has been much attention given to critical points in life such as changing job, having children, divorce and moving house all considered potentially stressful phases. I have never heard or read about moving into a care home discussed in the same way in this context, perhaps because as the very last episode in life, to which there is usually a 'one way ticket' it is too difficult to contemplate or speak about for oneself or loved ones. The biggest issue for service users was isolation. Communication is also a key feature of the following chapter, and Chapter 9 focuses particularly on the relationships that service users, carers and professional colleagues had with social workers in the study hospital.

Returning home was often not as easy for service users as one might assume either:

'Discharge from hospital was seen by most (though not all) patients and their carers as evidence of success. It was often quickly followed by depression at the full realisation of how changed life at home would be and this was exacerbated by a sense of loss of the warmth and support of the hospital environment.' (Baldock and Ungerson, 1994:45)

Hence as has been argued (Beresford, Adshead and Croft, 2006a) continuity from the hospital social worker to bridge the gaps could be crucial especially where no constructive family support was available, as explored in Chapter 9 (9.2.7 and 9.3.6).

The following chapter on decision-making looks at the stage and events leading up to the move out of hospital. For some in the study this was probably the final big transition in their lives, for others just another discharge preceding a further admission or what Gordon Lishman termed 'the revolving door syndrome' (Lishman, 2006) for older people.

8 Themes of decision making

8.1 Introduction

This chapter starts by focusing on social care information for users and carers regarding post discharge support. Information on services, the reaching of decisions concerning the latter and areas such as 'choice' and 'consultation' follow. The purpose of the chapter is to address the first two research study aims outlined in 1.3 including issues of involvement in discharge planning and options available for service users and their carers. The themes are collapsed together in this chapter because of their close relationship to one another; knowledge about the alternatives and choice of outcome, whether or not that is a practical possibility, forms the crux of decision-making. I was also interested in how the big decisions on post discharge destination were made and whether service users received help to reach conclusions that suited them and their families. The second project aim in 1.3 regarding examining the role of the social worker is particularly relevant here.

As discussed in the literature review some studies have taken participation in the decision-making aspects of the discharge process as a main focus (SCIE, 2006). Notions of patient involvement have been around for sometime, they were present in the Patients Charter of 1991(DH, 1991) and emphasised in the NHS and Community Care Act 1990 (Great Britain, 1990. *op.cit.*). The prerequisites of full participation, ie knowledge and/or previous experience to draw upon, are not so frequently discussed, nor are the power relationships within both the hospital hierarchy and wider society, in which older people's position and views tend not to be heard (Powell et al, 1994).

8.2 Knowledge and 'being informed'

Leading up to planning for discharge, probably the most important knowledge that service user and carer participants needed to acquire – after information about their medical condition, treatment and medication, was on the kind of social care they could expect on leaving hospital. That could be, in the main, about: social support including lunch clubs, activities and help with shopping, which are mostly now provided by voluntary organisations; domiciliary care packages including personal care and domestic support, supported housing, residential or nursing homes.

A few service users were undecided about their future, which is looked at in section 8.8. Regarding care home admission, service users and/or their families had to learn about the process of finding and applying for a care home place including financial procedures.

8.2.1 Knowledge and information about care homes

Of those service users who moved on to a care home, a small number reported that they had been given no information about the home or care home life; nor had they been able to visit it. As shown in Table 8.1 only a few were able to actually visit their destination. Some had been to homes before, others left it to their family to make use of the information and make choices on their behalf. Frequently home managers would visit patients on the ward to assess their suitability and presumably to impart some information about the home they represented, as reported by Carrie (U06) Edith (U07) and Sam (U13). The difficulty of being sure that service users understood the question and/or their recall of events is indicated by Sam's response:

SF: "Did anybody talk to you about moving into a home and what to expect?"

U13: Not really, I got a rough idea when I got here." [laughs]

Later in the interview it emerged that Sam had both visited the home albeit only for "15 minutes" when he was given the chance to ask any questions, and the home manager had come to see him in hospital. Out of the 12 service users who were discharged to care homes only two were actually taken to view their destination, as shown in the table below, one on an overnight stay. The latter seemed in 2005 a relatively unusual practice as it meant keeping a hospital bed 'purposely' empty.

Table 8.1. Extent of service user participants' preparation for a move to a care home

Participants	Visit to care home
U01, U07, U15	Already been to home they were discharged to.
U03, U10	Visited other people in different homes
U09, U13	Taken from hospital to visit to designated home
U02, U05, U08, U11, U12	Most probably had not been to any care home before
U02, U03, U05, U07, U10, U11, U12, U13	Family members visited care homes in advance of decision being made for user to move there from hospital.

A few of the 12 service users did recall being given some information about the particular care home they were going to and what life would be like for them there. Although Hilda (U08) for example, said she could remember little of what she was told she seemed to have some confidence as to what she might be going to because of previous life experience working with 'children in care', albeit some decades ago:

SF: "What information were you given about moving in to this care home?"

U08: A little, I can't remember. I think I did ask questions, a bit but what the answers were, I can't remember."

Asking service users to look back at what had been a difficult time for most, it was often not possible to probe further for a fuller response for ethical reasons, as putting further stress upon service users could not be justified.

8.2.2 Information regarding financing of a care home place

Lack of adequate information for prospective residents and their families on care home funding was raised by the OFT Market Study in 2005 and was being looked at more closely by former CSCI, (now Care Quality Commission) research. The OFT (OFT, 2005:7) found that care homes themselves were often not clear about their pricing but the other difficulty for service users - for which there is currently no quick or easy answer - is navigating the extremely complex structure of benefits and payments, loans and contributions that has been amended and added to since 1993 (OFT, 2005). Taken with continuous health care funding, it is hard enough for social workers to grapple with (Bradley, 2003), let alone for most users and their families.

Doreen (C08) had difficulty in obtaining accurate financial information from her Aunt's (U08) social worker even though she indicated she had some prior knowledge and confidence through working in a voluntary organisation:

SF: "What was your opinion of social services, the advice or help that you were given?"

C08: She [the social worker] would try to be very helpful and that, but she hadn't been in the post long, and you know she did not know half the questions that I asked her. I sent an email in the end, saying that Hilda was going to be charged interest on the money that they are going to pay out on the property - she didn't know that, but you would think that someone in that position would make it their business or it's lack of training on the Council's

part, ... (For) Someone who is completely outside, doesn't know anything about it, it's very daunting."

Likewise another carer participant, Barbara (C03) explained how she and her sister realised that they had failed to grasp that there was an option to defer payments for their father Eric's (U05) stay at a care home following his discharge: "its so very confusing and I don't think they made it clear enough" she commented. Lydia (C06) was baffled by the rules regarding the assessment of her husband Harry's (U10) private pension and some weeks later when I met her at his care home she was still trying to find answers from sources such as the Citizens' Advice Bureau and Age Concern. Lydia felt quite strongly that neither the social worker nor the council had been clear enough and Harry was outraged by the whole system of paying for care home fees, which he described as "absolute injustice". Their situation is explored as a case example in Appendix 2.

Two other user participants, Edith (U07) and Bob (U11) whose families were in the process of sorting out financing their residential care directly with the social worker were nevertheless uneasy about the possibility of 'unpaid bills' in their name, but did not want me to contact the social worker on their behalf. During the interviews with users particularly, I frequently found myself stepping outside of the researcher role but this was, I believe, consistent with ethical practice. I tried to reassure Edith and Bob as much as possible, particularly about the security of their place in the home and I was able to draw on past experience to explain that it could take a while for the council to finalise assessments.

Joe (C14) however was complimentary about the advice he had been given on the financial assessment and funding for his father's care home fees:

"I was sent details on exactly how much he'd have to pay, so that was quite good. XXX [social worker] was good. I was quite satisfied with her. The only thing I wasn't happy about was the hospital as I've said." **C14**

The six other carers who had to deal with such financing were also content with the advice and support given by the social worker. Kath (C13) had been particularly pleased that the social worker had arranged for her daughter to take on the responsibility of this complex area. Service users' finance, can be extremely complicated and time consuming to sort out. Elaine (C11) described going back and forth between local government social service department offices, and the

Department of Work and Pensions on her Mother's behalf (see case example, Appendix 2).

8.2.3 Preparation for being discharged with a care package

For the six service users who went back home with a care package, information about the services appeared to be less of a crucial issue. However for all but two (U14 and U18), their care needs were probably lesser and their state of health better. For half of this group, home care was to be continued or slightly increased, for the rest it was a new service for which they were appreciative, (for example Annie (U17) already discussed in 6.9).

Jessie (U04) described a visit from a care manager in hospital to inform her about services available and assess her eligibility:

"I'm very bad at remembering who did what, I mean it just happened, I suppose somebody said, 'we could just look.. into the social side of it?' ..A chappie came to see me who was very patient and kind, and said the social things that.. there could be somebody who could come to look after one.. he could arrange that, it was called Rapid Response." **U04**

One service user was Teresa (U14) the focus of the Chapter 6 case example, who went home with a new and very complex care package. While, her family were impressed with the planning of the home care support, they experienced the communication of information about the detail of it and how it could continue to operate effectively or be changed were problematic.

8.3 **Choice**

8.3.1 Date and notice of discharge

Choice and/or consultation on date of discharge in a climate of delayed discharge legislation and a shortage of resources did not appear to exist. Patients in this study were simply 'told', though where a relative was involved, some prior discussions took place. Apart from Sid's (U12) situation, where his sister in law had hoped to delay transfer to a care home by half a day, most service users shared Jessie's (U04) view: "Well, I didn't talk to anybody about coming home. I just waited to say, for somebody to say I could come home. It's up to the doctor to say." (**U04**).

Chapter 7 on loss refers to some service users keen to return home and others who expressed more anxiety about leaving hospital. Lydia (C06) described what it was like when her husband Harry (U10) found out that he was going to be discharged to a care home when as far as he was concerned he was still ill:

“You were told before Christmas that we had to find a place for you, because they couldn’t do any more for you. And then you had a good spell, and they thought they’d keep in a little longer to see what they could do, and so that was through Christmas, and then he had another blip and she said ‘no I’m sorry we can’t do anymore’. He was very upset...That’s the worse thing, he wasn’t the only one in the ward that had to come out, and he was very upset because the chap opposite just cried and cried all the time.” **C06**

But in fact Lydia and Harry chose to bypass social services as detailed in their case example, (Appendix 2). Lydia found a vacancy, which they funded themselves, and they told me they were able to execute Harry’s actual move more quickly than the hospital staff had anticipated.

When it came to actually selecting a date some carers spoke of mix ups, such as Kath (C13) who was upset that she did not have the time she thought to bring her husband’s clothes into the ward so he could go to the care home dressed. Similarly, Amy’s (C07) brother in law’s (U12) clothes were an issue, but not the only one for them:

“We would have liked more notice. It was just quite a rush getting Sid’s clothes and things together, especially as his son wasn’t back yet and for Sid to come to terms with going into a home – he didn’t have long.” **(C07)**

As Amy indicates it was not only a matter of convenience and making arrangements, but a question of having time to adjust, which was covered more fully in the last chapter. Barbara’s (C04) family had also planned that one of them would accompany Eric (U05) her father, to the nursing home, as he was quite ill then apparently. But the day of discharge was postponed and it was not possible for the ambulance service to give exact times, making that even trickier for relatives at work: “When it was arranged for him to go it was done really quickly. We were never given a chance to go with him.” **C04**

The notice period for service user and carer participants to prepare for discharge was looked at in Chapter 7.

8.4 Choosing between care home or a care package at home

The choice available to those service users with more complex care needs was in theory between whether to return home with intensive home care or to move to supported living or a care home. To the best of my knowledge, only two people (U06 and U15) were offered the former, and Keith (U15) was still awaiting a place by the time fieldwork had been completed. A few service users had already been in receipt of home care and one of them, Sid (U12) had lived in supported housing prior to being taken ill, when it was felt that his care needs and health clearly required care home admission. For the majority the risk of living alone was considered too great, although two of this group were offered the chance of returning home with a care package (U09 and U13). Gertie's situation has already been discussed above (6.9). She was clear that she would only accept a residential home place. The other service user, Sam (U13) explained that he was too frightened of having another collapse, to be by himself at home: "I was totally on my own, just me and my mobile phone". Sam said that he had not had a personal alarm connected to the emergency call system and he did not know about the availability of this back-up support. Such circumstances could have similarly applied to Bob (U11). He described his relief at having people around when he fell in a care home:

"but you see I just can't stop myself, and I just hit it [the ground] with a terrific force. I never expected anything like that. Whereas if I'd had been at home I don't know what would have happened." **U11**

Flo, (U02) was an example of someone who if more intensive home care support had been available to her could possibly have returned to her home in a village which was over 30 miles from her daughter:

"I could just get my legs going 'cos I can't move them you see, if only they would try to walk me or anything. If only I could walk I could go home because I'm well in myself, but however I'll do whatever I have to do. I have no option, I'll just have to grin and bear it, but I'm quite happy." **U02**

Flo's ambivalence to her situation and concern for her daughter's position as her carer is further highlighted from this extract from later in the interview when she stated: "I couldn't possibly have gone to my home— my daughter lives in x and it would be too much for her to come."(U02).

A few service users actually lived with a spouse or relative and two of Carer Group B were in this situation. Mona (U03) I discovered, nine months after I met her, had

returned home to live with her son, Simon (C02) who I also interviewed. Simon had a different view of the options available for his Mother's future care; here he was referring to the difficulty of managing stoma care:

SF: "What about your Mum remaining at home with home care support, was that ever discussed?"

C02: No it was made clear that that was not an option...She needed constantly changing with her bowels...?"

His mother Mona spoke of not wanting to be a "burden" to her family and that she chose a care home place. I also asked her whether she had discussed her future care with any nursing or social work staff but she did not think that she had, but for the other son/parent and two couples returning home was not a possibility. In two of these situations the added complication was that the person requiring physical care also had advanced dementia. Kath (C13) however did not explicitly refer to this aspect of her husband's care needs:

SF: "Was there ever any suggestion of care coming in?"

C13: Well I think the amount of care that he would need – getting out of bed for the loo, and in and out of the wheelchair, no there was never any – the carers that come in for me, they'll come in 2 or 3 times a day but that wasn't the point."

This relative was too distressed by the separation from her partner of 60 years to talk about this issue further.

For a user participant Fred (U01), he said that his family gave him little option but to be discharged to a care home after a second hospital admission, rather than back to living with his sister, a frail elder herself. The part played by consideration of risk in choosing the type of care has been well documented (e.g. Huby et al, 2004) and was uppermost in the minds of many of the professionals I spoke to, particularly the therapists and doctors who referred to what were, in their opinion, often unrealistic expectations of families and carers.

8.4.1 Choice of care home

Choice of care homes was another aspect that featured in the interviews, with just under half of the participants commenting that there was not enough. As Bob (U11)

pointed out, the scope for choosing a care home was limited by actual places available:

SF: "Were you given a choice about where you were going to go when you came out?"

U11: Well, more or less, but there's not a very big choice because there's so few places vacant."

As will become apparent with regard to actual decision-making, some service users appeared to be not very interested in information or choices of care homes, preferring their relatives to 'take charge' as Bob indicated to me.

For those going to transitional care there was even less choice, just two nursing homes with beds commissioned en bloc by the local authority.

SF: "What do you feel about the choice for somebody like her leaving hospital?"

C11: Well I think there's just the one place they send people from hospital to and we didn't know what we were looking for. It looked ideal and I think for some people it probably is but for her it wasn't the right place and that became apparent quite quickly because she became overwhelmed by it all and I don't know what the answer to that is."

Elaine (C11) here and in the case example of Appendix 2, also highlights the difficulties for relatives with no prior experience of care environments of 'knowing what there is to know', i.e. what to look for and what questions to ask, as Zena (C01) indicates below. Hilda's (U08) niece Doreen (C08) had some knowledge about local care homes as her own mother in law was already in one, but she too felt negatively about the options in transitional care. Flo (U02) whose home was not in the same city as the hospital was sent to a transitional unit in her own locality but this caused anxiety for her daughter Zena (C01):

"We weren't given a choice at that time. From then on the care manager from X took over and we spoke at length with her, on the telephone. She was very kind, very nice and she said that a place had been found for her in a local authority home in her own area and they could take her So it seemed there was no choice, it was cut and dried, that's where she was going, until somewhere else was found for her... but because we knew nothing, of care homes up until then, and a local authority home may be a bit down market, so I was a bit concerned, a bit worried about that. So I had sleepless nights about it.... " C01

So Zena decided to view the care home for herself, unannounced, and both the care environment and the attitude of the staff pleasantly surprised her.

Location also restricted the number of homes that could even be considered by families as Lydia (C06) explained:

“I said I needed him to be in the village as I don’t drive and we knew there was XXX home, so the social worker sent me a list of them and it covered YYY and all over the place... And I said to her you know we’ve done all this travelling all through the winter to the hospital every day, and we are just about at the end of our tether really, so I said it’s got to be in the village.”

C06

Given that there are not care homes in every village and every part of the town, older people without transport could spend hours travelling on buses. The position for older people needing a home registered for the care of the so-called ‘elderly mentally infirm’ is even more restricted. One carer Rene (C12) explained how she travelled up to 30 miles in either direction from her and her mother’s neighbourhood in search of a suitable place. However two service users (U09 and U12) did state that there was a reasonable choice of care homes for them. Both service users concerned were nevertheless funding their own placements so the cost did not have to meet the local authority ceiling, in contrast to Joe (C14) who had this to think of as well as travelling distance to visit his Father: “There wasn’t really a choice as such; the social worker gave me a list. The nearest one to here, just down the road, is pricey, extremely so”. (C14).

Finally, as was discussed at the end of the last chapter, Gertie (U09) and another service user Keith (U15) wanted to be discharged to a care home, in the latter’s case the same one as his wife was placed in when he was admitted to hospital, while they awaited a supported housing flat. She has moderate dementia and he is her carer.

What was important to users in deciding where to go when there was choice available to them was not discussed directly. Harry (U10) expressed disappointment at not being able to play bridge or talk to anyone, while Sid (U12) certainly appeared not want to mix with other residents when I spoke to him. Hilda (U08) said she would have liked to observe others at least playing cards although she also said she was not keen on playing herself! For Edith (U07) food was a factor:

U07: “All I wanted was egg and bacon for breakfast and I couldn’t get it.

SF: Was that what was important to you for thinking about where you were going to go?

U07: Yes. My friend came the other day and we went across to the café for an egg and bacon sandwich... I asked every morning for egg and bacon – ‘you’ll be lucky’ - and I didn’t get it.”

The support that carers received in finding a care home place is looked at in Chapter 9 on user/carer experiences of social work. How service user participants and their carers reported on *adapting* to life post discharge was explored in the last chapter on Loss and Transition.

8.5 Consultation/involvement in decision-making

8.5.1 Social work role in decision-making

The part played by the hospital social workers in facilitating the making of decisions was not clearly described by any participants least of all the social workers themselves. The impact of planning post discharge residential or nursing care for users is also explored in Chapter 9; as a social worker commented: “But we’ve never been involved in that decision, its been cascaded” (S/W E). In their focus group the social workers went on to discuss situations where health professionals had reached a decision, which may not have even involved the patient and for the social worker to be informed and then sometimes be expected to convey that decision to that patient. This and the debate about responsibility for decisions on social care are further explored in 9.6.4

Service user and carer participants who could recall the events with varying degrees of clarity, referred to the actual process of reaching a decision about post-discharge location and care. For example one service user made it all sound quick and easy: “They just said would you like to go into XX (care home) and I said yes and that’s been that” (**U07**). However I later discovered from the interview with her nephew that a home visit had also been arranged to determine whether residential care was the only option for Edith. I did ask most users and carers whom they first spoke to on the subject through to the final care planning. The following outlines the stages of decision making which were pieced together from the data:

- Information gathering for multidisciplinary (now 'single') assessment
- Initial conversations or 'broaching' of the topic of discharge often in general terms which appears to have been initiated by either nursing or social work staff
- Identification of resources
- Negotiations that may be combined with care planning at a multidisciplinary meeting and/or home visit with relevant professionals. Two older people referred to discussions with doctors and social workers on the ward, probably the 'ward round', rather than attending separate meetings
- Finalising of decision and location for discharge seemed to be largely achieved via telephone calls with relatives.

The social workers did mention these aspects of their role but somewhat fleetingly in their focus group. Experiences of the way in which professional opinions were conveyed to service users and/or their relatives are discussed under 9.5.

8.5.2 User Involvement in discharge planning

The language that service user participants used to describe how they felt decisions were arrived at is revealing. Fred (U01), for example talked about how he was consulted about plans for his future in what was a matter-of-fact tone:

SF: "Right I'm also interested to know about whether you felt consulted about where you were going to go?"

U01: Yes because the family all met together and they decided."

In reality, for the majority of service users, the family played a major role in concluding that a care home would have to be the outcome of a hospital discharge. Carrie (U06) was undecided about her future as discussed below, but she spoke of the pivotal role played by her daughter and the professionals, particularly the doctor:

U06: "Well, I wasn't actually there but my daughter saw various people. She seemed to take charge, and asked all these questions. I thought he was a lovely Doctor, you know, I thought he was very helpful. He said, 'I am on your side you know', I'm quite sure, between them, the doctor and the care worker and housing they got together and the doctor said what was wanted."

However another carer, Elaine (C11) explained that her Mother, who had dementia, had been given the chance to try a care home in order to decide what was the best option for the future. In the end she returned to her own home with a care package

with “100%” support from health and social services apparently as explained in her case example in Appendix 2.

Some of the carers, talked about making a decision based on evidence of the older service user’s state of health, as was the case outlined by Rene (C12) with regard to her Mother:

SF: “Can you remember when you first started thinking about her coming out?

C12: My brother thought she would come home, but anyone with any sense could see she wouldn’t come back home because she wasn’t walking properly anyway at all since she did her hip so you knew there was no way she could live on her own how she was.”

Hilda (U08) was not impressed with being given the chance to make a decision about a permanent discharge location in a transitional care setting:

SF: “People say its better to decide not on a hospital ward but here, what do you think about that?

U08: Well its also better to decide not on a hospital ward, not *here*, but what you would like yourself – which is *not* the same thing at all..”

Like Hilda, Mona (U03) had told me that she had decided for herself that she could not go home. She also knew that arrangements were going on behind the scenes although the following conveyed a momentary sense of uneasiness:

U03: They all seem to know, but I haven’t actually talked to them.

SF: How does that make you feel?

U03: It doesn’t bother me love. No good is it. No good bothering. Somebody has to look after me.”

Mona did also go on to say, in a confident manner that her family who visited care homes on her behalf, knew what she was looking for.

8.5.3 Consultation on home care package

Those older service users who went home with a care package generally had less complex needs. Jessie (U04) for example described her discussion with the social worker to set up home care:

“I thought he was very, very good really, just went through a form like most people do really in a way and, said, you know, it’s up to me to decide what I would like...” **U04**

Annie who seemed to have gained from the hospital episode, in that she was pleased with having home care post discharge, but she did not think that all the services provided were necessary initially. She could not recall any of the discussions she had about planning for her discharge, but said she was surprised when equipment arrived. It is not known whether this was sent ‘just in case’ or whether she had discussed with the OT what she needed. However Len (U19) had been in hospital for a second leg amputation and he and his wife recalled discussions to arrange home care and equipment post discharge. Home care needed to be increased to assist his wife and carer to help him mornings and evenings and with bathing. The couple explained that they were asked what times would suit them for home care. Nora (C15) his spouse also confirmed that the hospital staff had consulted with her about Len’s homecoming about which she was very positive. Steven (U18) also went home with an increase in home care. He gave the impression that although the social worker did not spend a great deal of time with him discussing this, as outlined in Chapter 9, there were probably not many options left open as home care had already been provided, but he would have liked to receive longer visits

The actual scope for choice and consultation on packages of care as explored in this section is clearly circumscribed by the operation of home care by council and private agencies, and the provision of authorised equipment. The reality of living with a care package and the follow up or continued therapeutic interventions for some service users were looked at in the Loss and Transition Chapter 7.7. Choice and consultation around home care seems to still be restricted to possibly having some say about time of visits according to the hospital social workers.

Nevertheless, none of the service users question this status quo apart from Stephen (U18) who was actually only in his late sixties but quite disabled by his ill health.

Furthermore, for him he said that it was the reality of care post discharge, often too hurried or inflexible, rather than the setting up of the service that troubled him.

8.6 Planning meetings

Four of the 15 service users with more complex needs were involved to various degrees in planning meetings on the hospital ward with their relatives and

professionals. To what extent these forums 'rubber stamped' decisions already made by staff at their multidisciplinary meetings is not clear from the data.

According to the staff involved, it was mostly carers or relatives that went to these planning meetings, although Zena's (C01) Mum (U02) came in at the end:

SF: "How do you feel about that meeting?"

C01: Well, I was quite distressed at the time, because things were moving on by then, and I didn't want them to, but it was having to face up to it and I don't think I managed it very well. But my brother was stronger than I was and I was suffering from guilt at the time, thinking that I was letting everyone down somehow. It's a bit silly I know, but that's how I felt about it.

SF: And was your mother present at the meeting?

C01: She came in latterly, towards the end, but I said she should have been here from the start because there was nothing said that we wouldn't have wanted her to hear... I thought she would be very, very upset to be told she wasn't going to come here, I was really worried, but she handled it better than I thought

SF: That was the first time she'd heard -

C01: Well I think X (social worker) had mentioned... but nothing had been said. We didn't want to upset her, nothing had been said specifically that she wasn't going to come home, but when it was put to her at that meeting she said 'Well I'll do what's best' she just accepted that, she said 'If you think that's best, that's what I'll do.'."

As Zena indicated in the above, Flo her Mother (U02), sought guidance from the family rather than making an independent decision about her future. Nevertheless, not all families wanted to influence their parents' decisions. Gertie (U09) for example, as in her case example (Appendix 2), described her son making it clear that she had to do what she wanted to be happy, even if that was "going to Mount Everest"! Similarly to Zena's position above, at the meeting that decided that her husband (U10) would be discharged to a care home, Lydia (C06) outlined her reaction: "it was a bit upsetting because we knew he didn't want to go out of hospital because he thought he needed hospital nursing."

One older carer Kath (C13) and another user participant, Hilda (U08) who did attend a planning meeting did not feel fully engaged in the proceedings:

U08: “we all sat round and talked about what kind of place I should go to and what I should have, what kind of bed... but you don’t remember afterwards what has been said

SF: Can you remember how you felt about the meeting at the time?

U08: I felt as if it were all rather over my head... it was a very good idea, they were all very nice, they meant it kindly, but I thought: you are there, and I am listening and I know its about me, but I just didn’t want to know...

SF: Is there anything they could have done to make things easier for you, do you think?

U08: A lot slower, but of course they didn’t have a lot of time. I had my solicitor there and he was saying he was going to have power of attorney...”

The impression was given that health and social work professionals in Hilda and Kath’s (C13) situation failed to convey any sense of empathy with users and carers unused to official discussions about often very personal aspects of their lives. Kath a relative who met with professionals about her husband’s discharge plan told me that she had an overwhelming desire to laugh, being escorted in to meet a row of people with clipboards, and no-one really seemed to know her husband very well in her opinion.

This carer, Barbara (C03) explained how the decision for her father (U05) to go to a care home was reached:

C03: “They informed us that they had come to the end of the road of what they could do and it was more or less the case that he needed full time nursing care and we more or less had to start looking for places then...we only had the one meeting with them. There was the social worker and I forget who the other lady was, some liaison officer X?

SF: The discharge liaison sister?

C03: Yes that’s right we did meet with them and they said they would talk to my Dad if we wanted them to and explain ‘cos at that time he didn’t know, he imagined he was going back to his flat, bless him. So we said “No, no that’s our job” so they were pleased with that which was good, but we never had any more meetings or anything it was a case of looking for somewhere for him to go.”

Eric (U05) was in fact very poorly in hospital at the time and it is unlikely that alternatives were available or possible. There was not the opportunity to explore in the interview whether a return home with an intensive care package had been discussed with the various professionals. Eric had readmissions to hospital from the

nursing home where he died less than six months from discharge. Some reservations about the format of planning meetings were also expressed by occupational therapists in the staff discussion group wondering if a smaller gathering could serve the same purpose and be more 'user friendly'.

Prior to the planning meeting the social worker had it seemed approached Teresa's (U14) daughter (C09) as discussed in the case example in Chapter 6 and talked to her about a nursing home, rather than domiciliary care package options, which they had found "very distressing" and is quoted in the section on Approaching Sensitive Topics in 9.5. Teresa's son in law (C10) goes on to explain how that experience therefore prepared them or "armed them" for dealing with professionals in the full planning meeting.

"We stood united and said we must have Teresa come home, that is a non-negotiable, there is no consideration of her doing anything but come home and we need to discuss what is going to happen. I don't think we would have been so aggressive in that meeting if you hadn't had that impromptu conversation beforehand which was distressing for you as well." **C10**

Unlike Kath (C13) above, however, for those who were not about to face separation from loved ones such as Keith (U15) the discussion with professionals about his condition post-stroke and the future was seen as useful: "Very informative, they told me exactly what was happening." (**U15**). Other carers such as Rene (C12) also found planning meetings instructive in terms of expert information imparted on aspects of their relatives' illness and how it should be handled.

8.7 Home visits

Key professionals from the hospital accompanied three service users on brief visits to their own homes to assess whether they would be able to manage there again and if so what kind of assistance might be required as described by Len (U19) and his wife, Nora (C15):

"They took me for a home visit. If I did what they thought was right I could stay if I didn't I'd have to go back! So I made sure I did everything they wanted." **U19**

This may read as if Len felt he had to pass some sort of test set by the experts. He did talk about the experience in a relaxed joking manner, although the words he chose were interesting in themselves. In contrast, Edith's (U07) visit to her bungalow did not go so well as recalled by her nephew (C05):

SF: “You were telling me that they took her home from the hospital.

C05: They fetched her at 2.00 that afternoon and left her there and she said ‘what do you want me to do?’ And they said ‘do what you normally do, make yourself a cup of tea’ and she asked me and she asked them – ‘do you want one?’ and oh dear she started making it with cold water ...And then they took her to her bed and she kept missing it so they said that would have to be altered and then they went into the bathroom and she missed the toilet and the bath. So they asked me my opinion and I said there’s no way she can look after herself

SF: So it was decided there and then?

C05: Yes.”

Perhaps significantly Edith did not mention the professionals visit to her bungalow in our interview and I had not been aware of it at that point.

The third service user known to have a home visit, Teresa (U14), was positive about the experience. For her and her family, it was part of an important assessment to gauge what help and equipment would be needed for her homecoming, which was apparently eagerly awaited.

8.8 Difficulties in deciding what to do

Edith (U07) was one of at least three in the group of 13 users, who did not return to their previous homes, and for whom it appeared that a decision about a move bringing more care and support had been an issue for a while. In her nephew Roy’s (C05) opinion Edith had been reluctant to leave her bungalow for some time and he indicated throughout the interview something of the pressure he felt under supporting his Aunt at home. Likewise Carrie (U06) and her daughter Diane (C04) described agonising about Carrie’s future in her large house and garden, as already noted in the previous chapter (6.3):

SF: “Another thing I’m interested in is when the realisation that she wouldn’t go back to her house, and how did all that kind of come about?

C04: Well, I think Mum had mixed feelings about it. I think in one-way she wanted to go back to how she was, but she realised it wasn’t an ideal situation. She couldn’t manage the house, it was a big three bed roomed semi, and the garden, and she was struggling with the garden anyway before she was poorly, so, but she liked her garden but she didn’t want the work involved in it. She’s lived there for 56 years, it’s a long time to change. My mother’s never been good with change anyway. “

Maintaining a garden as well as a relatively large home was an issue of concern here that did not crop up in interviews with other service users, but might be a common difficulty for older people in more rural areas. When I interviewed Diane's (CO4) Mother, Carrie (U06) who had been living in supported accommodation for a few weeks, was still debating whether this move had been the right one:

“I felt I was being pushed from here to there, for my own good, and somebody else was acting on my behalf, because I didn't particularly want to come here. And my young daughter who's the practice nurse, she said “Mum, you'll be better off where you are”, but I said “you're getting waited on hand and foot here, and I'm not doing anything”. I wanted to look after myself but she didn't think I could manage...I can you know..” **U06**

Sid's (U12) situation as a widower who had found it very hard to cope in supported housing without his wife has already been looked at under the heading of 'bereavement' in the last chapter (7.9). Sid said that his family had “bullied” him into accepting residential care but according to sister in-law Amy (C07): “We sort of gently persuaded you that you needed more care”. Sid had been living in a residential home for a fortnight when I met him and he was not enthusiastic about his new lifestyle.

8.9 Summary and concluding comments

Decision-making and how service users moved to a new location or back to the old one - but often with support services - are important components of their experiences of the whole discharge process. This chapter has given an indication of what those processes were like from user and carers' perspectives, in order to respond to the first of the project aims as in 1.3. It includes comments on the quality of services that very often they were encountering for the first time,

8.9.1 Lack of user involvement in discharge plans

In the literature review the lack of user involvement in discharge plans is highlighted as an area of long-term concern (Horne, 1998, SCIE, 2006) that may have worsened since reimbursement was introduced (CSCI; NAO and CHAI, 2006; Counsel and Care, 2005). The Department of Health recommends that date of discharge be decided from admission or prior to admission (DH, 2003a) and the study participants seemed to expect that the doctor make the final decision; although some of them expressed disappointment in the amount of notice they were given. Doctors were keen to insist that patients and their families were involved in

all aspects of treatment/discharge planning but said there were growing numbers of older people with dementia who in their opinion were incapable of taking part in such dialogues.

Involvement, participation and empowerment are important issues for social work but are particularly controversial in the study context partly because of the hierarchical nature of the hospital as a social system and because like democracy, the more parties to consult the longer the process takes. Some participants highlighted difficulties they had in keeping informed about social care plans following discharge and physiotherapists expressed reservations on this matter as detailed in 9.6.4. Some of the literature suggested that social workers have not always fully involved the service user or at best have not recorded discussions on their outcome (Marsh and Fisher, 1992). However the hospital team were under great pressure to perform assessments speedily and often, with little notice given, to find resources quickly from a reducing pool of both domiciliary and institutional care, and at the same time to liaise with family and other professionals including providers.

8.9.2 Planning meetings and home visits

The chapter also continues the exploration of service users' and carers' experiences of the discharge process, the first of the project aims in 1.3. For the minority who attended planning meetings an impression was given that some did not feel particularly included in the conversations about their own future, their presence was physical and I suspect tokenistic. On the whole home visits by members of the multidisciplinary team were more popular with study participants. These were also key tools in hastening a decision on whether a patient would be fit enough again to return home. In a few families (e.g. of U06, U07 and U08) it was reported that there had been discussion for some time as to whether it was safe for the older service user to remain living alone. The hospital admission then seemed to be the critical tipping point leading to change.

8.9.3 Delegation of decision making

Asking users about their perspective on being involved in their discharge was problematic in itself, in that in response to the question "how were you involved in the plans for your discharge" the answer was often "my family decided", and said in a positive manner. This delegation is looked at in the literature review and as

discussed at the start of the chapter can be seen as an active step for users rather than a passive abdication. Recovering from illness, being in hospital and undertaking treatment or therapy were enough for most to cope with, although a few service users expressed awareness and to a lesser extent unease about plans being made without their knowledge. Furthermore as Lymbery points out there is a difficult balance between autonomy and protection: 'many family members understandably emphasise the need for safety in decision making' (Lymbery, 2005: 31). A few users were also adamant that although they had little or no choice regarding a move to a care home and which home, it was *their* decision.

8.9.4 The financing of social care

Lack of understandable financial information regarding application for care home places was specifically singled out, and echoed earlier studies (Wright, 1998). The much promoted policies of 'personalised budgets' or even 'direct payments', for users to have control of their care, was never referred to here. Furthermore it is the social worker that is responsible for applying eligibility criteria for services and to the funding panel for care home financing, thereby the system further excludes users and carers. It is not surprising that few service users were taken to see a potential care home let alone given the support that may be required for the user or carer to be assertive and fully involved.

8.9.5 Choice of post discharge location

Choice is a complex area. For most service users who were discharged to a care home the option of remaining at home with an intensive care package was offered to a minority or was not practicable. There was widespread agreement between all involved in the study that the choice of care homes was poor and especially so for those needing specialised dementia care.

8.9.6 The social work role regarding information and decision making

I also looked at decision making in this chapter to address the second project aim outlined in 1.3 regarding examination of the social work role in hospital care management. Social workers new to the hospital team during the period of the research project told me they were given no specific training on care home financing and this is looked at further in the next chapter. Secondly, regarding the social work role in facilitating decision making, glimpses of this were given by participants, although only one user spoke of the assessment part of the process or help with taking or accepting difficult choices. Full participation in the hospital

environment requires any person, whether staff, visitor, volunteer or patient to be assertive, know what questions to ask, when and of whom.

The following Chapter 9 takes a closer look at how social workers related to service users and their carers, moving on to professionals' relationships with one another regarding discharges from the study hospital.

9 Relationship themes

9.1 Introduction

The purpose of this chapter is to continue to address the main aims of the research project as outlined in 1.3. It will therefore explore how interventions by the hospital social workers were perceived by the service users, carers and professionals as conveyed to the researcher during the individual post-discharge interviews and in the focus groups for staff. It will also specifically look at the effects of delayed discharges legislation upon the three groups of participants. The chapter is presented in three substantive parts. It begins with service user perspectives on their relationships with their social worker and that is a pivotal part of the study. To make some sense of the data gathered, the main themes have been selected which reflect the structure of the data generation process and what it was that participants wished to discuss with the researcher. This first part, from the user's perspective looks at:

- The social work role in arranging post-discharge care
- Constraints such as lack of time
- Information provision
- Relationship with the social worker
- Emotional support
- Follow up post discharge

The views of carer participants form the second part. Where appropriate, relevant comments from the social workers are introduced into the text, but their perspectives are looked at in more detail in the third part of the chapter dedicated to professionals.

9.2 Themes relating to users' experiences of social work

9.2.1 Social work role in arranging post discharge care

Out of the six user participants who recalled their hospital social worker, Keith (U15) and Jessie (U04) gave the clearest and most positive reports on their experiences.

They also had the some of the least complex needs and the least 'risky' discharge, as well as some choice of service as highlighted by Jessie:

"It was up to me to decide ...He was very kind and thoughtful and then when I changed my mind he was very patient and re-did the form." **U04**

Jessie was referring to the fact that she initially refused home care to assist her following her discharge. A religious and positive person, living in a supportive community, Jessie was also fortunate enough to be able to return home without question. Keith (U15) wanted to continue living with his wife who had moderate dementia, and who had been admitted to a residential home when Keith had a sudden stroke and went into hospital. He had cared for her for many years and the couple had been allocated a social worker in the community. Keith was able to wait on the ward for a vacancy at his wife's care home and because he had visited her there knew what he was going to. It may also have meant some relief and respite for this man for his wife to be looked after by care home staff. When I asked Keith about his contact with the hospital social worker - who had just introduced him to her new community counterpart, he was brief but enthusiastic:

SF: "What sort of things did you talk about?"

U15: Mostly accommodation

SF: You've got a new social worker now?

U15: Yes, if she's as good as the other two, there'll be no problems..."

Gertie (U09) an independent fairly active 90 year old who had fallen at home, gone into hospital, and then became widowed, spoke in glowing terms about her previous social worker in the community but talked less enthusiastically about her hospital successor. Gertie told me her consultant had tried to persuade her to return home with a care package, which it seems had frustrated her as she knew what she wanted - to live in a care home:

SF: "Did you see a different social worker in hospital can you remember?"

U09: The only one I saw came to see me and said we were going to have a discussion about where I was going to go with the doctor. But he thought I would be better in my own home, but I've no intention of living back there."

Gertie may well have felt her autonomy under threat from professionals within the hospital, and she talked about the atmosphere of conflict with her family “battling” on her behalf. When I asked her about her opinion of social work help with her discharge she replied somewhat tersely: “Well she didn’t come back to see me” (U09). The social worker told me later that she had conducted the review in the care home. This illustrates a difficulty for service users separating out professionals and the context of those relationships.

9.2.2 Constraints

User and carer comment about the lack of face-to-face contact with social workers is a reoccurring theme of the study findings. The study social workers themselves referred to having to conduct complex assessments in ten minutes, sometimes not even meeting the patient personally, let alone being able to give individuals much of their attention once the paper work was completed. Service users’ and their families’ appreciation of time spent was referred to in Beresford et al’s study (Beresford, Adshead and Croft, 2006a). Clearly Jessie (U04) was pleased about the attention her social worker had afforded her, in contrast to the lack of notice and rushed discharge at the end of her stay, which was the only complaint she had to make to me about the whole process. Keith (U15) too spoke about two or three visits from his social worker. However, Steven (U18) a user who returned home with painful ulcerated skin expressed ambivalence with the interaction with his social worker largely because of its brevity:

SF: “What did you think of social worker’s help?”

U18: I don’t know tell you the truth. I didn’t see enough of her to form an opinion. I saw her a couple of times in hospital. She was on leave frequently. She just paid me a couple of fleeting visits; I didn’t have a long chat with her. As far as I was concerned in hospital I was in doctors’ and nurses’ care and they were doing their best for me.”

In comparison with more visible physical care from health staff, it is probably harder for patients to fathom the role of social workers. I went on to ask Steven if he recalled what he discussed with the social worker in hospital, to which he responded: “Not really, just about coming out. She was arranging for this home care” (U18). Returning to the issue of time from the social worker I asked Steven his opinion directly:

SF: “Would have liked to have the chance to talk to someone for longer?”

U18: I would, yes, and find out what help you could get, as I say I didn't have much contact, but I'm used to being independent ...The social worker sent for an attendance allowance form, ages ago, for me but its still in the box in there."

After the interview Steven agreed I could mention the last point to his social worker, but in her opinion the form he was referring to was actually the home care contract, she knew nothing of attendance allowance, but said she would follow it up.

9.2.3 Information provision

Finances were a concern for a few of the other service user participants, who unlike Steven were in care homes and concerned about fees, such as Harry (U10), Bob (U11) and Edith (U07). Edith was more vocal about this aspect of moving into a care home than anything else and we carried on talking about it after the interview. I tried to reassure her that her nephew and the social worker were dealing with assessment for care charges and the sale of her property. From her anxious facial expression I sensed she was uneasy about the possibility of being faced with a large bill, having not been fully aware of how the system worked. She also expressed some disappointment about having to sell her old home. I discovered from her nephew (C05) later that she had gone back to her bungalow for a trial visit to check whether it would have been possible to install equipment to assist her functioning there, but he said there were too many cognitive problems faced by Edith then for anyone to consider this a realistic possibility.

The social workers' perspective on financial information and giving of information on care homes in general is discussed more fully in the second part of the chapter. It is perhaps important to note that the three service users in the study who went to residential homes and also recalled their social worker, had all been to the home in question before - Gertie (U09) for an overnight stay, and the remaining two had visited other people there several times. Furthermore they had all made a positive choice to be discharged to those locations. In that sense knowledge, albeit basic, of the residential setting did not impress as being something they lacked.

9.2.4 Relationship with the social worker

As with Edith and Gertie who relayed mostly positive views of discharge outcomes, so did Keith (U15) who appreciated the social worker's efforts to arrange a placement in the same care home with his wife. This desired destination was not

the only aspect however that he spoke of enthusiastically. As described above he talked about the social worker being “good” in a manner that suggested that he valued her personal qualities and their relationship. When Gertie spoke about her previous community social worker “even” coming with her to introduce her to day care she indicated how important it was to her that this professional had acted ‘above and beyond the call of duty’. Similarly as already described, Jessie (U04) was clearly impressed with the patience shown by the hospital social worker who had returned to carry out an assessment after she had changed her mind and decided that home care post discharge could after all be of some benefit to her.

Edith told me that the hospital social worker had: “made arrangements for me to come here” [the care home] but she could not recall what they talked about. I went on to ask her opinion of this help:

SF: “It would be useful for me to know what you thought about the help you had from the social worker?”

U07: She was all right.”

Unfortunately because the conversation had become rather stilted with silences, I momentarily forgot ‘best practice’ and asked a closed question:

SF: “Were you able to talk to her?”

U07: Yes.”

I deserved the response I received there and I was unable to probe any further as I realised that the detail of their discussions had almost certainly left little impression upon Edith.

9.2.5 Emotional support

Service user participants, who were able to talk about it, had a variety of emotional issues to contend with. Keith had been an informal carer for some years and was having to adjust to care home life, as was Gertie (U09) and Edith (U07), who expressed disappointment at the thought of selling her bungalow to pay fees. Gertie, while she was happy to be in the care home spoke at some length about the trauma of her husband’s sudden death. For those going back home Jessie (U04) appeared to be well supported in every sense, and Teresa’s (U14) family (see case example in Chapter 6) explained on her behalf that she was a private person more

likely to turn to family than to outside agencies for emotional support. Steven (U18) said he would have liked longer with the social worker and it was clear that he had a variety of needs that were compounded by deteriorating physical health. Chapter 7 looked at the situations for service users experiencing loss before during and after their hospital stay and adjustment post-discharge respectively. These included loss of home, independence and deterioration in health as well as bereavement and change of role.

9.2.6 Follow up post discharge

Finally 'continuity of support' welcomed by Beresford et al's research participants (Beresford, Adshead and Croft, 2006a), was conspicuous in its absence in this study, although as is described in the next section the carers had more to say on the subject. The hospital social work team as a whole were ambivalent regarding their responsibility to follow up service users in the community after they left hospital. Some of them felt this was an important part of the job, others complained they had so little time to do it and a minority of staff were clear that they believed once older people were discharged they, like the other hospital professionals, should cease involvement. However three of the six service users who recalled the social worker and also went back to their own homes, had some difficulties ranging from minor ones regarding timing of visits in Jessie's (U04) case, through to concern regarding care staffs' perceived attitude in Stephen's (U18) case to a need for additional support visits and clarification of tasks in Teresa's (U14) care package. Her summing up of the situation conveyed more than one message: "Social services were perfect. It was the implementation that was wrong...No co-ordination." **U14**

As discussed in the case example in Chapter 6, whilst Teresa's (U14) family thought it was possible that the social worker had telephoned her to check on progress post discharge, Jessie (U04) and Stephen (U18) reported that they had not heard anything from their social worker prior to the interview. Stephen furthermore told me that he had already been allocated a new community social worker. He said that he found this out when he contacted the council about obtaining a mobility scooter. Of course it is also possible that social workers communicated with all these service users post-interview.

9.3 **Comment - time to form relationships**

In the community, social workers tend to be involved longer term with service users providing greater opportunities for both parties to become better acquainted with one another. The lack of time available to the hospital social worker, to the extent that 'the relationship' formation is almost an unreachable luxury, has been discussed here and in previous chapters. However, for older people, often struggling with sensory and cognitive impairments, ill health, and lack of confidence in the whirlwind of activity in an alien hospital environment, attention from staff appeared especially important to them and was highly valued. Some of these themes will also re-occur with regard to the presentation of data from the carers' interviews, which follows.

9.4 **Carers and relatives experience of social work**

Poem: 'The Social Worker'

The news for you, the young man said,
Is that you have to find
A nursing home within a week,
I hope that's not unkind.
Our hospital has no more beds,
There's no more room: and so
Your mother with her mended hip,
Unmended mind, must go.

I have a list that you can take
With numbers you may ring
And what the cost will be. I think
That covers everything.
It's up to you. I've work to do.
No time to lose. And so
Remember, you have just one week.
Your mother has to go

By Ruth Silcock, 1996.

9.4.1 Background

The above poem usefully and powerfully reflects one perspective of the hospital social worker's role. Much of the following section considers how far this is a picture shared by both the professionals and carers or relatives who took part in this study.

The data from the interviews with the informal carers or relatives yielded more material to analyse regarding opinions on, and experiences of, social work

intervention in the study setting, than that from the user group. There are two reasons for this: firstly, all the carers I spoke to could recall the identity of the care manager unlike some other similar research projects (e.g., Stanley, Reed and Brown, 1999), and secondly they were either more able or more willing to talk about the contact that they had and at greater length than the service user respondents did. The carer participants certainly seemed more at ease in the interview situation, which may reflect less apprehension on my part, dealing with issues to some extent less directly. Apart from two meetings in care homes and another in my car, all interviews with this group were held in their own homes, therefore completely on their 'territory' and with more privacy than an institution could afford to user participants.

Another important theme that appeared in this study's carers' interview data was 'being available'. Accessibility of professionals is often mentioned in the literature (e.g. McLeod and Bywaters, 2000). In summary the following themes in relation to social work with carers of older people leaving hospital are discussed in this section:

- Availability and approachability
- Information provision
- Social worker as go-between
- Emotional support
- Continuity

9.4.2 Availability and approachability

Most of the carers were pleased that they could speak to the social worker at least on the telephone when they needed to. Barbara (C03) understood that the social worker was not always sat at a desk and able to answer the telephone, and commented: "They did always get back to me". Kath (C13) an older disabled woman commented that it was a comfort to her that the social worker gave her his card and told her to call him any time. Zena (C01) expressed relief that even when the social worker was on leave someone else was able to help:

"No, no they've been fine, and I do know you can get them on the end of a phone if you've anything to say but really I've got nothing to complain about. I did want to ask one thing but the care manager was on annual leave, so someone else took over, and they said they would find out and phone me back and they did." **C01**

However for Simon (C02) whose Mother Mona (U03) had three different social workers, none of whom he had apparently met face to face, he seemed mildly

irritated that there was no reply when he telephoned the social worker for advice on completing an attendance allowance claim form. Whether he tried to contact her more than once and how much pressure he felt under in general at the time, is not known.

As discussed in 9.2.6 above, according to some carers or relatives they did not receive a call from the social worker to see how they or service users were or how things were progressing from their perspective, once a decision had been made about location of care post discharge. For those whose social workers kept in touch, they seemed to particularly value the contact as expressed by Elaine (C11):

“Impressed by it and the follow up care as well because I thought once she left hospital I thought that would be it but the social worker kept in contact and the OT. ...The care in the community was good and I’ve met them too, the after care’s been very good.” **C11**

Elaine’s situation is further discussed in the case example (Appendix 2) but this does show how expectations of service provision can influence opinion. Barbara (C03) describes the opposite, of feeling almost abandoned:

SF: “So looking back over the whole thing, is there anything that you Would like to have been done differently?

C03: There could have been more communication throughout and with the social worker. You tend to get the feeling you are just a number, not personal. Obviously they’ve got a lot to deal with on a daily basis but when it’s you it’s a big thing. It was all very black and white to them but when its yourself there’s so many grey areas so I think they probably could have arranged to see us more, rang up to see how we were doing instead of us phoning them.”

The social workers themselves would not be surprised by this and believed that their management was preoccupied with meeting government targets to the detriment of the department’s caring role.:

“Its very much management culture now – business language, statistics returns and you sort of feel that the people get forgotten, that’s not the driver for management” (**S/W H**).

However Kath (C13) who was so devastated by her husband’s admission to a care home explained that she was not expecting the social worker to have contacted her and seemed not to mind. She commented that the social worker had been in touch

with her daughter instead, certainly about finances, which in itself was a relief to her. Kath received home care in her own right so had some support at home.

Implications for practice from the evidence in this data are fairly clear and are further discussed in Chapter 10. The social workers themselves had lamented the current state of affairs in which it was possible to admit someone to a care home without ever talking to the person.

9.4.3 Information provision

Philips and Waterson noted that carers in their research project having to choose a care home: “wanted advice, guidance, recommendations and someone to come back to if things went wrong.” (Philips and Waterson, 2002: 181). Carers and relatives in this study said that they appreciated being given more than just a list of homes to choose from; and in the case of Simon (C02), as reported in the last chapter, even his list was inadequate. However this did not apply in all cases. Another carer, Joe (C14) told me he was happy with “just” having a list and that he did not think that the social worker actually knew much about the individual homes, but Joe seemed happy and capable of approaching establishments himself. He was articulate and told me he had no other major commitments. Rene (C12) explained that she and her family wanted to check out the few EMI homes for themselves, but work and the necessity of travelling long distances made this difficult.

The remainder of the group, whose relatives were going into self-funded placements, had a mixed experience. While they had a choice and were not limited to transitional care places, three families said that they were given no assistance apart from ‘the list’. On the other hand Amy (C07) told me that the social worker had been very helpful and that there were plenty of residential homes for her brother in law in the area they wanted. The policy of the council is to provide an advisory service to self-funders and there used to be a dedicated post in the hospital just dealing with this group to facilitate discharge and ease pressure on beds.

The giving of a list of care homes to families and not much else was apparently a widespread practice (Wright, 1998; OFT, 2005; SCIE, 2006) and the CSCI commissioned their own research in 2007 on how people choose care home places to encompass this area. In addition some studies have gone further in concluding that care managers do not have enough time to give the support needed in this respect (SCIE, 2006). Certainly local voluntary organisations confirmed the findings

of this study. The other connected findings were that very few people had any idea what to expect in a care home, what to look for or had any experience of being in one, even visiting one, in order to make a comparison. Hospital social workers were usually unable to take service users on introductory visits to care homes, or often even to make follow up visits to them once they had been admitted. That leaves a gap for carers and service users who require information to make an informed choice and as Zena (C01) commented:

SF: "Can you say something about the opportunity you had to ask questions about homes and what to expect?"

C01: Well anything I wanted to know I asked her but at that stage I didn't know what to ask. I had to find out for myself. My daughter she looked up about homes on the Internet. They are looked at by an independent body."

Obtaining information on the financing of care home places was another issue for relatives, as reported in Chapter 8, with three families having major problems with this. In two cases the service user speculated that they suspected the social worker was new to the job or locality. One relative did manage to find out the information she needed for herself (C06), but for the second carer (C08) the problem was an ongoing one. She was not only exasperated with social services, and governments for developing such a complex system, but also by contradictory advice from voluntary organisations and friends. A social worker in fact commented in the focus group that she found the financing systems for assisting older people to pay for care home places very difficult. One of the social workers, in their anonymous feedback on the research wrote that s/he realised more training was needed, but at that point this was not provided routinely to social workers new to care management or to the council. Indeed, I have also outlined Barbara's (C03) situation in 7.2.1. She was worrying about informing her Father that a nursing home was the only option for him, while the social worker was explaining the finances and Barbara told me she was only given that one opportunity to find out what she needed to know – an illustration of lack of sensitivity in communication from the participant's perspective.

Past research has shown how a system of care home financing which is intrinsically unfair to older people, can also be further inequitably applied by social workers and administrators who have discretion:

'Lack of knowledge of the legislation, insufficient clarity or openness in local procedures, inadequate training of practitioners, coupled with local economic

and political expediency, create an unstable culture in which the justice of the system is called into question.’ (Bradley, 2003: 653)

Interestingly the doctors in their discussion group talked about users and carers being ‘more informed’ about health conditions and services than in the past. However it was not clear what the source of the knowledge was, the media including the internet, past experiences, or successful information giving by social services, as a social work participant put it:

“I think we are getting to the point now where some of the older people and certainly a lot more of the carers are a lot more informed now than they were about what is and isn’t on offer on discharge.” **(S/W A)**

9.4.4 Social worker as ‘go-between’

The role of go-between as identified by researchers who have looked at social work and hospital discharges (Phillips and Waterson, 2002) can be interpreted as a more passive form of advocacy in this context and there is clearly some overlap or merging of roles. For example social workers in the study made requests to the wards for older patients to be discharged at a time that was helpful to relatives, or to keep a bed for a patient who went on an overnight stay. Talking to doctors on behalf of patients or relatives, a role identified by other researchers (e.g. McLeod and Bywaters 2000), was not mentioned by any of the participants of this study, although some carer participants saw obtaining medical information as problematic.

Where users were unable to take part in their own discharge planning due to cognitive or physical impairment, as was the case with four families in the study, the ‘go-between’ role appeared to be prominent. Carers (C12, C13 and C14) referred to social workers not only liaising with care homes and wards but also acting as a ‘go-between’ with the user who was usually unaware of their own need for permanent care and the relative who often found the whole situation very stressful.

Lymbery discussed the role of care managers as bridging the gap or advocating between service users and social service management responsible for resources (Lymbery, 2005). Carers demonstrated some awareness of the general way the system of financing operated, particularly when it was deemed unfair as reported by three of them (CO2, CO6 and CO8). This may be because as they were paying for their own care home costs they took second place to those who were local authority funded in the competition for scarce care vacancies. In fact Mona (U03) and her son (C02) both recounted how she had been all set to leave hospital and with little

notice, lost her nursing home place to someone considered a higher priority apparently for that financial reason, according to the social worker.

9.4.5 Emotional support

Some researchers have concluded that: 'Most people wanted help with emotional and practical or financial matters; the two emerged as closely interlinked.'

(Beresford, Adshead and Croft, 2006b: 2). Lydia (C06) summed up the unmet needs that she felt she and her husband Harry (U10) had as: "A little bit more talking to you [the service user]; a little bit more help" **(C06)**. Hospital social workers echoed the experiences of the user and carer participants, typically: "There isn't the opportunity to do social work, to sit and talk to people like we used to do, I mean it's 'in and out'." **(S/W A)**.

Some carers indicated that they had struggled to cope at home and realised that they could not continue when the user was discharged from hospital. Difficulties for them still existed nevertheless in observing the care in a nursing home that, in their view, was not of high enough quality and adjusting to a new role and life without their parent or spouse. The evidence on whether social workers were providing emotional support to carers in spite of pressures of time and administrative duties is difficult to assess. None of the participants described anything other than practical tasks being performed but the way some of them talked about their relationship with the social worker and their body language suggested that they were deriving some emotional support from the interaction.

One of the social workers spoke enthusiastically about a session she had been able to have with someone who I believe was a relative of a patient, although the implication was that for her this amount of attention for one 'customer' was more unusual than usual. Nevertheless it demonstrated to her that being able to give time to an individual makes a difference:

"I suppose you get good days and bad days like any job and I suppose that I'm relatively new but still the bad things are outweighed by the positive which is the 'one to one'. But I spent a lot of time with a woman on Friday and she was amazed that I was able to spend that amount of time. Not only was she grateful, but she'd never had that amount of involvement with social services." **(S/W C)**

However most of the few relatives who were asked directly denied that they would have wanted emotional support from the social worker, some preferring to seek it from family or professionals they had known for a long time. Whether their views would have altered if a more in depth or longer-term relationship had been established with the social worker is not known. Another group from the carers sample appeared to be either coping very well or not in need of anything over and above what they were receiving. Nevertheless it does not follow that those who presented in this way did not require it or should not have been offered some form of emotional support. The effect upon emotions that followed the breaking of 'bad news to service user and carer participants is covered separately in the next section of the chapter.

9.4.6 Continuity

Helping carers finding a different role for themselves post discharge particularly when the service user is discharged to a care home is highlighted in past research (Davies and Connolly, 1995; Wright, 1998). The part the social worker is able to play here depends to a great extent on whether they can carry on being involved post discharge, that is whether they are in a position to offer continuity as referred to in 9.2.6 above. Hospital based social workers are uniquely placed to act as a bridge between home, or care home, and hospital and to oversee the co-ordination of care packages that they have commissioned. In the study hospital however the discharge liaison sisters conducted some follow-up work with older people discharged with more complex needs. Two thirds of the carers in the study still had the same hospital social worker although some were preparing for a change to the reviewing officer.

As reported in Chapter 7 in relation to post discharge adjustment, the changeover was problematic for two of the relatives for different reasons. Gill and her partner (C09/10) had difficulty in locating an allocated worker to sort out some issues with her mother, Teresa's (U14) care package because the hospital social worker had transferred the case at the point they were trying to make contact. The problems could have been addressed had the hospital social worker spoken directly to Gill and Malcolm following Teresa's discharge. Apparently a call had possibly been made to Teresa herself, but as she was dysphasic, conversations particularly on the telephone were not easy for her as discussed in her case example in Chapter 6. For Elaine (C11) her Mother with advanced dementia did not seem to accept or relate so positively to the female reviewing officer they had been allocated, compared to

the hospital social worker. Moreover co-ordination became a problem in both situations as Gill (C09) understood they would have to wait six weeks for the care package to be reviewed, and Elaine would have to wait twelve months for her Mother's review, in spite of an increase in home care wanted for both. A third relative Joe (C14) was anticipating the change from social worker to reviewing officer for his Father who moved to a care home. He was clear that he would have preferred to have a named practitioner to consult with in the future, as there were already concerns about how his Father was being looked after at the care home.

Researchers describing users' and carers' views of social workers seem to concur that 'continuity of support' (Beresford, Adshead and Croft, 2006a) is a much-valued part of practice. The social workers in this study discussed the issues at stake for them in keeping involved with families – and two of them referred to 'a big gap' left by users leaving hospital without an allocated worker, as cases are only kept open for up to six weeks:

S/W B: But that's the problem we can't respond to the hospital and the fast work we do, its difficult as it's the client that suffers in the end.

S/W C: But people's problems don't end here do they cos I've had someone who went to transitional care and she had a house to sell so I've been in touch with her and her relatives and now she's back in again I've been to see her on the ward and her niece who's got power of attorney about factual matters like finance and things I don't really know enough about. But I'm the only name they've got and I'm still in touch with them.

S/W F: Why should you – you've done your care management job”.

Carers varied as to their expectations of the social work continuing post discharge. Lydia (C06) said pointedly that “no-one came to see you” in the care home even though she and husband Harry (U10) had decided to go ahead with arranging his move into a care home without social services' support and funding. Elaine (C11) however was delighted that her Mother's social worker kept involved not only post discharge to transitional care but also after she left there to return home and sounded surprised about the follow up, as already quoted in the first sub-section above. Lydia, Harry and Elaine's situation are all looked at more closely in the illustrative case examples (see Appendix 2).

9.5 Approaching sensitive topics with service users and their families

How service users and carers received and reacted to the more negative or difficult news that might be given in hospital is the subject of this separate section. I was impressed with the significance that the event 'of the telling' seemed to hold for some service user and carer participants.

In the following extract Rene (C12) whose Mother had a multitude of health problems including dementia and a broken hip described what was to her an insensitive response from the Consultant:

SF: "Did you have a meeting on the ward with any staff?"

C12: Yes we did, the only time I had a meeting was with my two brothers and the doctor after she had broken her hip Obviously she was in pain as she would not stand on that leg, they put her on it too soon and he wasn't very nice the doctor when we asked him about it, no bedside manner, he said 'well she's dying' not, 'you expect something after all she's been through', but not to come out so bluntly. I think he realised after a few days and she picked up again..."

Edith (U07), one of the older service users, relived a ward round during which she was clearly angered and upset by doctors and nurses attitudes to her regarding her progress in hospital:

U07: "Yes. I remember one doctor saying how did I feel about going home and I said 'oh all right, I feel as if I'm going from strength to strength', and he just laughed at me.

SF: What did you think about that?

U07: I wasn't very pleased. And the nurses that go round with them, they just laughed, as though I was simple."

Another service user Annie relayed the details of an encounter with nurses who she perceived as laughing *at* her, after she had gone up to the nurses' station during the night. In both cases the laughter could have been meant in a warm and a sympathetic way but not in the opinion of the patients.

Like Edith above, Fred (U01) who had been in both hospital and in transitional care before, had still not imagined that he would not see his home again:

U01: “Ay yes it was a shock as I expected ... I expected to go home and just improve, because the nursing sister who used to come every day... they were very good, if I wanted anything they would bring it.”

Fred’s family seem to have taken responsibility for taking the decision and conveying it to him.

Nurses had apparently in two other cases raised care home admission initially with relatives or the patient before involving a social worker:

“First of all the senior nurses mentioned, they didn’t sort of make an issue of it, you know, but they mentioned in passing, ‘now have you have you thought about what was going to happen to Mother?’ because it was becoming increasingly obvious that she wasn’t going to get back on her feet again ... and, I think perhaps because the fault was with us, that we didn’t accept that very well, we were so hopeful that she was going to get better.”
C01

This relative gave me the impression that she was grateful for having the idea of a care home place for her Mother introduced in the manner described. Simon’s view on the way in which heard similar news about his Mother with whom he had always lived was quite different:

SF: “So when did you start thinking about her discharge?”

C02: I was told? It was just dropped on me when I was visiting her one evening. They had told her that afternoon that she would have to go into a home

SF: So were you surprised about that?

C02: Yes, I just expected her to come home.”

To be fair it is not possible to ascertain either exactly how staff engaged with service user and carer participants about these matters during very fraught times, and whether regardless of how sensitively conveyed the message was it would have not been well received. For example I asked two other relatives about when they started thinking about their Mother’s discharge:

C09: “Before that point we kept saying what’s happening, what’s happening and I did go in and I was on my own and the social worker said ‘oh can we have a chat?’ I found it very distressing because it was going down the whole line of you’re [i.e. her mother] completely dependent so you’re probably not looking at going home because you’re not going to be able to manage and if you didn’t go home you’d probably have to sell your property

and it was not like we hadn't thought of those things, but its not something that we'd considered."

C10: That was very distressing."

Another carer was concerned not so much by how she came to realise the future for her Father, Eric (U05) but the context in which the information was given. Barbara (C03) was preparing and thinking about imparting the outcome of the assessment to Eric herself, whilst grappling with care home admission procedures. Both social worker and discharge liaison sister had offered to 'break the news' but this had been rejected:

"We knew we were going back to tell my Dad that day that he was going to be going in [to a care home], it was an upsetting time for us all 'cos although he knew in his heart of hearts he wouldn't be able to go back, he was trying to convince himself that he was, bless him. So we knew he was going to be upset and so while they're *telling* you things you're still thinking about having to do that as well, so I don't think you do quite take it in. So maybe if they'd had us back a week later and asked us how we felt about things and is there anything else you [we] weren't sure about?" **C03**

The issue for the carer, Barbara (CO3) here seemed to be lack of support afterwards, and being expected to take in other complex information at the same time, as discussed above (9.4.3), that was not the priority for her then.

I tried to bring up the topic of raising sensitive subjects, such as potential care home admission, with the social workers themselves, who focused on the actual decision making aspect:

SF: "The other thing I've picked up is that people are totally devastated not to be able to go home even though it maybe unrealistic, they've clung onto that -

S/W E: But we've never been involved in that decision, its been cascaded

S/W H: Its very difficult though to get it back, once that decision is made, to pull it back."

Although a valid and relevant point was being discussed here the conversation then changed tack to focus on the negative aspects of care management: "I think care management has lost its focus, it should be informed by social work as G said it's a process you can train monkeys (for)..". (**S/W D**). In other words the issue of users'

and carers' perspective of 'tough' outcomes for them and how that news was delivered and received was lost.

Continuing with data generated by the health and social work professionals I met with in the hospital, we look next at the main themes, which emerged from that material.

9.6 Professional perspectives

9.6.1 Introduction

The data referred to in this part of the chapter was generated by separate focus group discussions with social workers (**S/W**), occupational therapists (**OT**), physiotherapists (**Physio**), doctors (**DR**) and discharge liaison nursing officers (**D/L**) involved with older patients discharge in the study hospital. Findings most relevant to the study's aims of exploring the perspectives on social workers relationships to other disciplines in the context of the discharge process, are organised under the following headings:

- Constraints upon professional endeavour
- Inter-professional working
- Staff views of older patients' involvement and decision making

The numbers of professionals who took part in each focus group can be found in Table 5.4 in Chapter 5.

9.6.2 Constraints upon professional endeavour

The effect of reimbursement legislation

S/W A: "More target driven, performance indicators-

S/W B: That's been influenced by the reimbursements as well, that's changed it – the two together, really."

Here in the social work discussion group two practitioners summarised the major influences upon their work over the past few years. Later in the session they went on to talk further about 'tick-box' managerialism and also the increase in administrative, often computer-based activity, which was described as equally burdensome by all professional participant groups in the hospital.

The discharge liaison sisters summed up their perspective on the implications of delayed discharge legislation for this hospital:

“There is pressure on social workers and all professionals to communicate more effectively, and between wards etc. Wards vary and staff vary as to how successful this is. But delays have decreased considerably and there has been a growth in intermediate care and rehab facilities. So reimbursement has helped to identify the gaps in resources, but hasn’t improved relationships between health and social services here.” **D/L A**

Regarding the penultimate point about service gaps, these have been highlighted in the literature for a while (e.g. Means, Morbey and Smith, 2002) and there has been confirmation elsewhere of a growth in much needed ‘step down’ services (Askham, 2008). Otherwise this was a mixed picture, not unlike the physiotherapists’ views about the legislation in this context:

SF: “What are your views on reimbursement and the effects it’s had?”

Physio A: I think they should have got more funding and staffing for the social work side of things. There’s no point having the funding coming in and then not providing the service to allow for that.

Physio G: And it is down to how many physical beds there are out there at the end of the day, I think there is a waiting list for every home in the area. It has given a sense of urgency and focus.”

Similarly the doctors thought that the legislation had brought forth improvements in reducing delays for some patients, but in their opinion it had not gone far enough, and had resulted in the social services adopting unhelpful tactics:

SF: “What impact do you think that it has had on the discharge of older people in this hospital?”

DR A: Two fold probably. It’s helped some people but those poor patients transferred out into the community for a longer period of rehab, they are not counted in those figures in rehab. I think the general feeling is that a lot of patients in the community units are further delayed because they are not part of that delayed discharges bit.

DR B: Social workers became very defensive about it. That’s probably because they were being managed not to have Section 5s and it was almost like performance management coming in. I thought that was a very unhealthy environment for all concerned because people weren’t thinking what was the right thing to do for the patient any more.”

The doctor above referred to his view of how social services were dealing with reimbursement. Research from CSCI (CSCI, 2005) on the effects of the legislation has found health and social care brought closer together to tackle hospital discharge efficiently and effectively. However at this site staff 'on the ground' painted a picture verging on disharmony, as the doctors went on to discuss:

SF: "So has it affected working relationships in the hospital?"

DR B: Yes I think it has. It changed things as much as anything, so there was a whole set of rules new guidelines which people had to adhere to and interpret. Different people interpret things in different ways and still do.

DR C: It seems to have created a barrier between health services and social services, because of this legislation. I certainly feel that.

DRs A&B: Yes, yes

DR C: Them and us

DR B: Completely separate camps now aren't we?"

The negative effects of the reimbursement legislation upon staff relationships referred to here was something that the House of Commons Health Committee (2002) had warned about, reinforced by social workers in the study hospital:

S/W I: "It's driven the whole process really.

S/W C: It's provided a real barrier and on some of the wards it's definitely 'us and them'. If there's a problem particularly if it's housing or even a placement it's seen as 'our fault'. If you're trying to get a suitable place for someone or suitable housing, it's like we're causing the delayed discharge which I try and keep myself distant from but they talk about people's lives as though they're causing a problem because they've not found a place and they're ready to go, a 'blocked bed'."

Far from having a positive effect upon the discharge experience for older people it seemed that while numbers of delays might have reduced, social workers believed that older patients caught up in the system may have had negative attention towards both them and social services legitimised. Additionally, the concern that the numbers of delayed transfers of care are being reduced at the expense of improving the quality of the process has been commented upon (Henwood, 2006). There was also some debate among the occupational therapists (OTs) about the desirability of the legislation for older patients:

OT D: "To some extent it is ageist because I don't think younger people are treated like that ... Younger people can occupy beds just as long..."

OT B: Yes but I think the services we have for older people are good.

OT D: They're good but I sometimes think we expect – we've just had a 90 year old with a fractured humerus... she lived alone. I'm sure you wouldn't expect a younger person with a fractured humerus to go home within two days so why are they expecting a 90 year old to go home?"

When presenting these findings to the social work team, the last sentence found strong agreement with that group. It raises human rights issues, which have also been identified by other commentators on the subject (Ford and Stepney, 2001). Few other professionals said much about the impact upon older people themselves, but I asked the social workers directly:

SF: "What about the older people themselves? What do you think has been the impact on them?"

S/W G: The number of times you know I've had clients say 'I just feel I'm being pushed around'. They say: "I'm going home tomorrow and I've not seen the physio yet". They just feel a bit rushed I think."

Some of the service users interviewed individually certainly felt that they were being rushed, which links in to the general trend of faster patient turnover, considered in the next section. I asked all staff participants their opinions of the effect upon older people of *delayed* transfers of care and this is looked at in 9.6.3 below.

9.6.3 Faster turnover of patients

Increasing numbers of people have been treated in hospital over shorter periods, in line with government objectives. Clearly the delayed discharges legislation has been one factor at work, combined with techniques and treatments that can be performed more quickly or locally, and older people have seen the abolition of long stay hospital beds.

The impact of fast turnover of patients, explored in past research (Payne et al, 2002; Atwal, 2002), was acknowledged by all groups of staff, apart from the doctors who seemed concerned with an increase in the number of older people with cognitive impairment on the general medical wards – "there is more demand just from the number of people in this category". For social workers particularly reliant for their 'bread and butter' daily endeavour on relationships with older patients and their families, the shortage of contact time had hit hard:

S/W C: “There isn’t the opportunity to do social work, to sit and talk to people like we used to do, I mean its ‘in and out’.

S/W H : I don’t think they have time to do the nursing either.

S/W B: You’re discharging someone you’ve met once for 10 minutes, you talk to them for 10 minutes and then arrange a package of care or placement and you don’t know that person.”

Later in the focus group a social worker went on to describe this process as being akin to ordering a takeaway pizza, which struck a chord with the whole group. They did however speak of occasionally being able to spend a little longer with a patient and how important and helpful that had been for both parties.

Some of the occupational therapists were equally sceptical about the level of health service to older people:

OT D: “More acute fast track sticking plaster, people are just in and out.

OT A: You know its only going to get worse building these new services with community matrons over them, which will put more pressure on beds, to get people out even quicker, that’s what we’ve been told.”

No one else had referred to the impact of community matrons in this way. Some of the OTs in the group also spoke about the rise in readmissions witnessed for some wards, which had been identified by the social workers too, but this was difficult to assess due to the way each hospital admission is categorised as a consultant episode in the statistics.

In contrast, while the discharge liaison sisters believed “standards had improved considerably” overall they were critical of performance targets particularly in Accident & Emergency as: “they do not allow enough time for a thorough initial assessment of older people’s needs, especially when they are more complex.” (**D/L A**)

Assessment, or the Single Assessment Process (SAP) as it has come to be known, is a whole area that deserves attention but is beyond the scope of the thesis, and SAP had not been implemented at the study hospital during the research period. Other research has looked at challenges to its introduction including ‘territorial

disputes' and 'border controls' and how these might be overcome, both relevant to this study (Cornes and Clough, 2004).

Both a social worker and a physiotherapist in their respective groups used the analogy of the factory *conveyor belt*, to describe the experience of discharge. The social worker identified a specific role for social workers which has been highlighted in previous research (Phillips and Waterson, 2002):

“for the older person, we’re the only profession that takes into account the loss and the change and the fear and that they are on a conveyor belt. If it wasn’t for us trying to put a stop to that it’s deeply worrying.” **S/W B**

The physiotherapists explained how speed of ‘treatment’ affects different older people differently, but the hospital discharge operation did not take individual needs into account:

SF: “Would you like to say how that’s affected the older patients?”

Physio G: I think it does vary, like any set of patients there are those elderly patients who its very easy to move on quickly and they are fine with it and no problems and there are other patients who don’t take well to it who are perhaps put on that conveyor belt and its not as easy for them and not as easy a discharge, and sometimes pieces have to be picked up afterwards...the push is to get people out whether they feel comfortable or not actually!”

Here discharge seems to be governed by a medical model, an opinion that was raised by the OTs in their group. Nevertheless, when asked the doctors emphasised the importance of psychosocial factors, in relation to patients’ abilities to cope at home, motivation and so forth, when assessing ‘fitness for discharge’.

Attitudes to those older people waiting in hospital

All groups of staff expressed concern for older people still found waiting on the wards although at times their negative comments towards families seen as procrastinating or waiting for a placement of choice was surprising. Having listened to her colleagues’ wishes that families could be fined - like social services - and the need for other people to access treatment, one Physio spoke up for older patients:

“I’d hate to think that they were labelled by that. That’s the ultimate horrible thing that they then feel they are a burden and labelled ‘bed blockers’ by the press” (**Physio F**).

This comment concurs with a similar observation previously made by researchers on the effect of delayed discharge publicity impacting upon older people’s self image (Littlechild and Glasby, 2000). During a similar discussion with the Occupational Therapists there was a debate about the possible institutionalising effects and the rights of the patient:

OT A: “And its quite frightening for them when they do have to go, like that lady, she’s used to the people and the environment.

OT D: But its right why shouldn’t you wait for the home of your choice, why should you have to accept the first one?”

The doctors spoke in a comparable vein to OT A above, about physical and psychological effects of waiting on wards once a patient is pronounced fit for discharge, the matron who joined in pointed out the poor environment endured by patients as well as the impact upon the morale of staff:

“I think it takes a major toll on staff too. Nurses come in and they say why is this person just waiting and waiting? The environment’s rubbish on these wards...” **DR A.**

Interestingly I had imagined the opposite taking place, with reports of nurses not having time to get to know patients fully that a familiar face might be welcomed!

The social workers were the only professionals to talk in the focus groups about the possibility of older people’s health improving in hospital after a while, especially with the opportunity for further rehabilitation although this was not always available to these patients. Another social worker expressed her concern regarding attitudes of the clinicians towards them:

“They feel like a spare part who shouldn’t be there. The Doctor bypasses them. I think people can feel uneasy.” (**S/W H**)

It is surely an inevitable consequence of fast turnover of patients on a ward that those not quickly discharged may feel set apart.

9.6.4 Inter-professional working

Seeking a user's perspective on joint working was not easy because of a lack of recognition of the role of either agencies or agents involved, as has been found in previous research (Stanley, Reed and Brown, 1999). Only two older service users mentioned the topic.

All professional groups participating commented that team working varied considerably from one ward to another, but could be effective in the hospital. Both discharge liaison sisters and social workers were felt by therapists to be "good for advice" but the social workers and the doctors were also described as being on the periphery and not knowing the patients so well. All the longer serving health professionals nostalgically spoke of the period up to the mid 1990's when a social worker was attached to a ward physically and in terms of responsibility. According to Doctor B they: "knew the details of the cases as well as I did and would tell me what the right thing is to do". In contrast he felt that the current arrangements were: "a good service when it comes but its reactive rather than proactive, going around delving whilst the person is there on the ward." **DR B**

Asking the social workers a slightly different question about how they were valued, produced a response that resonates with the views of social work from many of the other professionals in the multidisciplinary team:

S/W F: "We've probably got different experiences haven't we? It depends who's in charge of the multidisciplinary team. I feel like I'm... well we're often left out of the loop aren't we when someone's discharged, even into care homes, certainly domiciliary care as well, and you have to fight really to be included in the loop.

S/W B: We're tagged on at the end aren't we, when the decision is already made where somebody is going, then they involve the social worker to pick up the pieces.

S/W F: It doesn't matter really if we're seen up on the wards daily or if we attend team meetings on a regular basis."

This discussion then led to a disagreement about whether it was preferable for the social worker to be based in an office on the wards, which was raised again later in

the group interview. One of the most experienced workers commented that being in closer proximity to other staff on the wards had led to inappropriate referrals and requests such as being asked to do a patient's "laundry".

The modern matron who took part in the doctors' focus group pointed out that nurses might have to liaise with "four, five, or six different social workers now". For social workers it has always been the case of being outnumbered by personnel from other professions and therefore having to liaise with more than one nurse or doctor etc. One of the social workers also explained that turnover of nurses was so high that it was hard for them to 'get to know' one another professionally.

9.6.5 Inter-professional tensions

While the discharge liaison sisters responded that all professions were valued equally, some of the physiotherapists explained that they felt sorry for social workers who were caught in the 'middle', and had difficulties in obtaining scarce social care resources. Another physiotherapist became increasingly vitriolic in her response referring to social services from a neighbouring authority:

"I know it's difficult for them to come down and talk face to face but we are having quite a lot of difficulty with them. They often come back with continuing care questions and, from this point of view seem like stalling tactics often. A lot of it is fairly basic stuff and come on, you know this patient could have been home by now!" **Physio G**

A social care perspective on these 'stalling tactics' might be that a social worker was acting on behalf of the service user, to give more time for a fuller assessment or decision making for example, many commentators believing that such action is perfectly valid (McLeod and Bywaters, 2000).

However underlying tensions were not just evident between social workers and the rest. Two OTs made illuminating comments about the status of their professional assessment of whether an older person might be fit for discharge, as one put it:

"They do say someone's 'physio safe', but they don't say 'they're OT safe so they can go home', so you're not only having to justify to doctors but also to physios who say 'they can stand and walk'. On the other hand on orthopaedics they don't discharge if you haven't finished with them." **OT B**

The role of the doctor, to whom all professionals have to justify patients' presence on the ward, came in for some criticism. There was agreement when one of the OTs

gave instances of doctors having told older patients they were ready to be discharged when they patently were not in their opinion:

“They don’t always know best. All that patient *hears* is: ‘I can go home’, then they see us as putting barriers in their way, when we’re trying to make things safe. Its still this lack of understanding, its still this very medical model, not interested in the social situation.” **OT D**

During the feedback session with the social workers the last sentence had resonance for them also. However there were some strong feelings about other professionals performing aspects of what had traditionally been key parts of the hospital social work role.

9.6.6 Overlapping roles

Social work staff were keen to talk about other professionals doing their job, a subject that aroused strong emotions and that has been looked at in previous research (e.g. Reed and Stanley, 2000). In this first extract this first extract from the social worker focus group, the discharge liaison nurse role is scrutinised by the social work team:

S/W C: “I think that the role of the discharge liaison nurse, the very name, they have taken over our role somewhat, they liaise with the discharges.

S/W D :It was quite astounding really on one ward, the doctor decided this chap needed to come into care so he knocked on the discharge liaison sisters’ door and said ‘This man needs to come into a care home, can you suggest some places where he could go?’ So by the time I was involved it was really bad as he didn’t need to be in a home and then he didn’t want to go into X rehab unit as his wife had been there, so he ended up going to Y rehab, but the chap got quite distressed by it all”.

In the opinion of the social workers being ‘left out of the loop’ had serious repercussions for older patients as in the case cited above, and other examples were given of users and carers not receiving information about social care in time.

For their part, the discharge liaison sisters were clear that in their opinion it was they who had the expertise and time required to work with older patients who have complex needs:

“I do believe that you have to look at the whole person and it does need an experienced nurse to make a judgement about what kind of care is needed especially for an older person with very complex needs. There are so many

things to take into account, including the risks to consider, and the social worker, to be fair, may not have the knowledge and experience to.” **D/L B**

Given the experience of many of the social workers in this setting, this perception of their capabilities was somewhat surprising. A discharge liaison sister did go on to comment that she would become involved with families and visit them post discharge as: “care managers don’t have the time to spend on these things” (**D/L B**) so perhaps this lack of time again was partly the ‘key’?

Occupational therapy also appears to either overlap with social work in this hospital, or to have filled a gap that social workers are no longer able to cover themselves. The social workers seemed disgruntled by this ‘encroachment’ as was conveyed in this extract from their focus group:

S/W F: “OTs are very good at doing our job especially in care of the elderly. We often get notification forms with ‘needs residential care’ and we think what’s the point?

S/W H: They’ll tell you how many times a day they need the care.

S/W B: Every home visit report we get back from the OT, a lot of them will say recommend 24 hour care or she lacks capacity, all these words bandied about but nobody has asked the patient what they want. Then we have to manage that risk and its difficult for us as well as you’re aware that there can be huge risks at home and you’re worried, however you’ve got to give them that choice

S/W H: There’s stuff to do with management and risk as well. Other professionals are much less prepared to take a risk than we are.”

In addition to promoting older peoples’ rights and independence, the social work participants felt strongly that they had a unique professional stance that set them aside from other staff working in the field. Furthermore they brought this holistic approach to care management, technically open to other professionals now, and they believed that this was of benefit to older patients:

S/W E: “I think you’re right, other people do our job and I think that nobody else can do our job as holistically as we can. Nobody else sees the bed, home, the family and everything else, the life of that person.

S/W I: We do use our social work skills when we are doing assessments and dealing with people.

S/W F: You don’t need to be a qualified social worker to be a care manager.

S/W G: The only way it can rise up from the food chain and cascade, it has to start from the top, to work successfully with health... I think we're going to be displaced as an autonomous profession, we'll be replaced and become health and social care."

This last sentence refers both to the social workers' views of the way their management has worked with acute trust management and reflects the widespread concern of social workers that social care will become subsumed by 'health'.

9.6.7 Staff views of older patients' involvement and decision-making

Many commentators have made criticism of a lack of involvement for older patients in their discharge planning since such issues first began to be debated (Glasby, 2003). Findings from the professionals' groups gave some indications of a lack of consultation with service users leaving the study hospital and this is further explored below.

The following gives an insight into the social work group's attitude to decision-making, the tussle with other professionals and the role of the older service user in the 'melee':

S/W F: "We are representatives though of the local authority who provide this care, surely we are the ones who determine level of need, ok we do it in a multidisciplinary, but the decision is with me who goes into residential care, not nursing, but residential, but how many times do I do that?"

S/W H: Should you decide or the patient?

S/W F: The patient but I should decide the level of need and the eligibility

S/W C: We often get involved after they've had a case conference with the family, the decision has been taken, they're going into care. We say, "Have you spoken to the patient" if you like and they say: "oh no" and we got told on the ward rounds "can you go and talk to the patient?" The decision has been taken and you just can't believe it.

S/W I: I'm not used to that, I'm used to being included all the way along."

Improvements that could be made in discharge planning as expressed by physiotherapists, included better communication with the patient who, it seemed, could be overlooked even when it came to being given a date or time of discharge, let alone involved in any decision-making:

Physio E: "I think if I was the patient I'd be very confused about what's going on. A certain amount goes on with the family, but a lot is done behind

the scenes, that we're aware of but they don't need to be aware of, but at times it can be frustrating, as nothing seems to be happening.

Physio B: A lot of the time we assume that stuff has been said to the patient. They are asking us 'what's happening' and we just assume that the nurse whose looking after them has told them that you are not going home today or tomorrow, and sometimes that's not been passed on. They still think they are going home that day and they've not been told and they're just sitting waiting and no ones actually said: 'we don't know the time'."

Occupational therapists were adamant that, whenever possible, they would always locate the carer or nearest relative for background information, and to agree on discharge arrangements. Decision-making may take place at a visit to the patient's home or a case conference. Four out of the seven older service users in the study who returned home told me they had benefited from discharge care planning meetings, which were informative and helpful. Nevertheless, occupational therapists reported that when relatives need medical advice, as had been the case for one study carer, rarely was a clinician there to give it. The doctors themselves confirmed that they "don't usually attend" such meetings, stating that they had every confidence in other staff, which is arguably somewhat missing the point. Furthermore, case conferences, which deliberated upon a course of action with patients and/or their families, were not surprisingly more difficult and in the words of a physiotherapist could be "intimidating", with students also swelling the numbers present. As one older service user put it: "It all went over my head" (U08). She commented that a slower pace would have improved things.

Doctors talking about informing and involving patients and relatives in their discharge plans explained how this may be far from straightforward when there are communication or family relationship difficulties, or the patient may be at risk: "Patients need to be consulted at all times about their discharge; it's their discharge, its them that's going home..." **DR B.**

Brief reference was made above to choice between discharge to their own home and some form of institutional care for some service users. In a situation of balancing risk social workers spoke about their role in promoting patients rights to self-determination. All professional participants agreed upon the lack of choice of post discharge care homes for older people in the area. A social worker and an OT also explained that the *client centred* ethos of their professions was under threat:

“I think from the OT point of view we try to give people the option or choice and if they don’t want to go to rehab we try to abide by that. I do think from some of the staff on the ward there is a kind of pressure to get them to agree to go because it means an acute bed is freed. I think it’s quite hard to be client centred and keep saying it’s your choice.” **OT B**

Nevertheless a different OT in the discussion explained that for her, having the option of intermediate care, enabled her to continue to be ‘client centred’, in that older people “can be ‘rehabbed’ [by] enabling carers in their own home.”

The social workers associated the eroding of a client centred approach with the operation of care management. This was in fact in contradiction to the supposed ethos of user involvement that was set out in the original national policy:

“I think over the last few years its got more moving away from social work and into more of a model of care management, certainly less client centred.”
S/W F

Whether the centrality of the client's position has been reduced as a product of speedy discharge procedures or professional priorities, the outcome is clearly the same for older patients whose needs may be secondary to a smooth running process. Linked to choice of care home, its location is of undoubted importance to service users and their families. A discharge liaison sister described intervening to prevent older people being discharged to care homes a long way from their home town. The social services department of a neighbouring authority were apparently pursuing such placements in order to avoid fines.

9.7 Concluding comments

In terms of meeting project aims of 1.3 in the three main areas of service users’ experiences, the operation of care management and the effects of delayed discharges legislation, the data analysed and presented here gives wide coverage of most points. Some difficulties that were encountered, such as older service users’ recall of social work and separating out the effects of delayed discharges legislation from other health trends, are looked at in Chapter 11. However the findings from the professionals focus groups proved to be fuller than expected and the differences and similarities between the data sets is discussed at 9.7.3.

In summary there were a few reports of outstanding social work support and practice in the findings, and also some minor criticism. Nevertheless, as stated earlier, I was surprised to hear any negative commentary, particularly given service user participants' selection for the study by social workers and the positive impression that I had formed of the team during our extensive period of interaction. However there has been a longstanding tendency of older age groups to give positive feedback on services (Manthorpe et al, 2008; Carr-Hill, 1995). The contrast with the Social Services Inspectorate report of 1993 findings is clear, as there were many references in that to service users appreciation of social work intervention and relationships with practitioners and no negative comments from older people were included (SSI, 1993). However, this is not to compare like with like as that report looked at several local authorities' social service departments, not just the *one* as this thesis does.

9.7.1 Lack of understanding and fear of social work

It is apparent from the data that many of the service users did not understand the role of the hospital social worker and were unaware of activity they conducted such as 'assessment'. Of the six user participants who talked about their experiences of contact with a social worker, three of them as reported had had previous experiences to draw upon and comparisons were mixed in terms of favourability. The social workers for their part blamed the change of job title and, to a lesser extent the role change to care management for users' uncertainty, although confusion regarding the nature of social work has long existed, mixing up the remit of Social Security with social services for example.

In their focus group social workers made reference to the 'fear factor' and the influence of the mass media image as found in other studies (Beresford, Adshead and Croft, 2006a). The occupational therapists also spoke about older people's fear of 'being taken into care', the misunderstanding of terms such as 'rehab unit' as well as the confusion they, as OTs, had about the roles of other professionals in the hospital, in spite of their advantage in wearing uniforms and having equipment or physical therapies to promote.

Furthermore it was felt by some social workers that within the profession and local authority as well as the hospital environment, they had not been clear about the limits of their role themselves: "...for many years we've had no clear understanding of our role and just picked up anything that was thrown at us ..." **S/W D.**

9.7.2 Associating social workers with circumstances' beyond their control'

I have also looked at how sensitive information or decisions were conveyed to the patients and their families in 9.5 above. Being the bearer of 'bad tidings', or even association with the traumatic events and the ensuing arrangements for care, may have been factors helping to produce negative recall of social work intervention. This was certainly an issue that emerged in the interview with Teresa (U14) and her family. Conversely, user and carers can sometimes feel that they are being pressurised to return home as in Gertie's (U09) case (see 9.2.1 above).

Although I did not ask users directly about this, some of them expressed anxiety about paying care home fees and two were forceful in their disapproval of the system for care funding. There is therefore the danger that social workers can become linked to local authority means-testing and during my study I witnessed convincing argument that this can interfere with the relationship with service users or carers.

9.7.3 Different concerns of different participant groups

Not surprisingly even common issues often carried different weight for the two broad groups of user/carers and professional participants, for example, 'follow up' which was a contested area within the social work team, was felt to be more important for the users and carers. Similarly only two of the users and carers spoke about interagency relationships at all. Both Fred (U01) and Gill and Malcolm (C09/10) expressed opinions that poor communication had impacted negatively upon their situation. There were also areas of broad agreement between some participants from all three groups such as on fast turnover of patients and lack of choice of care homes for older people.

In the social work focus group, in which they were asked about factors affecting their practice, the increase in administrative duties concerned them. I did not introduce provision of information as a topic, which was an issue for carers, but neither did it arise in the conversations except in relationship to financial assessment for care home fee payment. There was also some agreement that older people could be left waiting for information of different kinds, although most of the professionals were at pains to reaffirm commitment to involving everyone in decisions and that the whole process from assessment through to discharge could be rushed.

Being emotionally supportive to users and carers can clearly be time consuming for practitioners. It seems that social workers had little choice but to prioritise assessment and care planning functions of the care management role, i.e. the arrangement of post discharge services and the associated administrative procedures. This was of vital importance to users and their families too, who although they may have been unaware of all the behind the scenes activity were also affected by how the tasks were handled and their relationship with the social worker. The table in Appendix 9 shows and compares more fully the concerns of staff and user groups.

9.7.4 Interprofessional relationships

The data from the professional groups contained some surprises too, for example, the manner in which post reimbursement, inter-professional relationship 'strain' was described. I was also struck by the way in which the poor media image of social work appeared to have been reinforced by the low standing which these hospital social workers seemed to feel that they had in this particular setting. Conversely the health professionals spoke more confidently and assuredly about their role in relation to hospital discharge. I had assumed that the social workers played a pivotal part in the co-ordination of older patients' discharge, but was told this was not the case in 2006. To hear some of the strong views of professionals about the families of older people waiting on wards for discharge were somewhat alarming and I hoped this was not the 'tip of the iceberg'. However there were a few counter arguments of concern for the position and feelings of older people in that context.

The next chapter further explores and discusses the practice implications of the data presented in this chapter, and also that of the preceding thematic chapters on loss, decision-making and transition.

10 Discussion of the research findings

10.1 Introduction

The purpose of this chapter is to bring together the substantive issues identified in Chapters 7-9 and to look at what can be validly learned from the study findings in order to meet the aims of the research project in 1.3. Both the interviews with users and carers and focus group discussions with professionals generated some rich data presented in the preceding chapters. A number of common themes emerged that not only shed some light upon older patients' experiences of loss, transition, decision making and relationships but also raised issues about social work practice in the hospital setting.

In this chapter I firstly discuss the methodological implications of the research findings and start by returning to the philosophical approach to the study, as covered in Chapter 4. Drawing upon data presented in Chapter 9, the concept of social work practice that is hidden or invisible; and the issue of service users' lack of recall, are explored. I then discuss policy and practice implications including partnership working, before turning to the responses of professionals, service users and carers. A synthesis of what was valued by users and carers is developed from the data presented in the three previous chapters. This is followed by a discussion of the meaning for social work discourses. Finally I pose the question how do the study findings link in with the current debates on the nature of social work?

10.2 Main methodological implications of study findings

10.2.1 Phenomenological approach to the study

Obtaining the essence of participants' 'lived experience': a characteristic descriptor of phenomenology, was difficult mainly because of time constraints for various reasons, not least due to the length of time service users were able or wanted to give to the interviews. Nevertheless with the benefit of hearing voice tones and seeing their facial expressions and non-verbal responses within the context of the interview and its setting, my aim has been to, represent potential meanings that were clear to me at the time (see basis for approach in 4.3.2) while staying as close as possible to the testimonies of those participants. I have where reasonable suggested interpretation, but only where there is direct evidence in participants'

accounts, where there have been similar findings in past research or where instances have coincided with my own experience of social work practice and I am able to draw upon that experience and knowledge. The latter has mainly applied to material from focus group data and where I have sought to reach another layer of interpretation - to seek hidden meanings. This in turn has raised further questions and dilemmas and altered the direction of the thesis to a focus on social work practice.

The practitioner and service user knowledge constructed is outlined in the rest of this chapter, the latter enabling further reflection for hospital social workers. The creation of knowledge in this context is further discussed in relation to perceptions of social work activity below. In all of this however, I am mindful of reliance not only upon participant's interpretation of past events and thoughts but also how they wish to respond to me as researcher in that time and place, and how I reflect upon and present those findings. My goal has been to take care with my interpretation of the data, in much of which meanings are often unclear and I am left posing alternatives or queries or stating that uncertainty.

In the case example and in the presentation and analysis of the last three chapters I have tried to convey as much as is possible on paper of what it was like for service users in and out of hospital, including their dealings with social workers. Given some older service users did not talk at length about their experiences of leaving hospital or they could not recall the detail, interpretation relies upon 'the ordering of themes and of acquiring an intuitive grasp of contextual data' (Morse and Field, 1996:127). Thinking and writing about participants in composing illustrative case examples was useful in this respect, in that they convey more fully the lived experience for the individual. Being able to check with Teresa, the written story of events based upon her interview was both illuminating and gave rise to further material as reported in the addendum. Likewise taking part in the focus groups gave staff the opportunity to contribute to the interview agendas and to feedback on the experience verbally and in writing afterwards.

10.2.2 Hidden Social work

Bearing in mind the observation, 'what you do not see you cannot describe. What you cannot describe you cannot interpret' (Patton, 2002: 262), I would liken the search for the detail of the less obvious aspects of social work in the study context as like looking at a mirror which was reflecting back much of the practice I knew so

well. However it was the tiny specks on the 'mirror' that were more interesting in terms of the research aims and these minute particles could only be seen in the 'light' or from a certain angle. As already stated much of social work activity was beyond the 'mirror frame' altogether as for ethical reasons I was unable to interview those service users who had communication difficulties, including cognitive impairment. The social workers as the gatekeepers to the sample excluded any referrals involving sensitive situations including those of serious family conflict, or ones with actual or potential adult safeguarding concerns.

One question I have consistently asked is what is it that these hospital social workers undertook with service users and carers that might have been hidden from the study because of the reluctance or inability of participants to describe it to me? As observed in reviewing government inspections in 3.2.3:58 above, it is a great deal easier to talk about the performance of practical tasks, than to describe counselling or emotional support or even reassurance. Clues as to opinions of social work input including how they handled the relationship or assessment and care planning and so forth, were often found in user or carer participants' non-verbal gestures, a smile or a nod or a pause. An inkling of the meaning of social care for users and carers is given in the following summary of an account of the care of a dying woman:

'How the quality of my mother's life and death were enhanced and her last wishes fulfilled was kept invisible to the official bureaucratic eye. For what really mattered was the creative fusion of the practical, emotional and spiritual in everything they did, fulfilling with dignity the deeply touching possibilities of care practices.' (Ferguson, 2007:3)

The social worker's way of conducting the day-to-day business, that was so much appreciated, forms the bedrock of the profession's tools, but may be summed up by many a recipient in brief phrases such as "she was very nice". Herein lies the conundrum for the researcher attempting to use data generated from service users and carers.

Nevertheless the importance of the clues given by service user and carer participants must not be brushed aside or minimised. The conceptualisation of practice given the evidence available can only be touched upon here, but further reading on the area was helpful in perhaps magnifying the 'specks on the glass'. Carter and Everitt in their exploration of practice with older people in the arts or

health promotion spheres concluded that: 'The notions of friendship and conversation in their very ordinariness, express what is most important in the best of routine practice.' (Carter and Everitt, 1998: 98). Moreover although they defined friendship involving 'reciprocity among equals', they name social work as an activity to which the concept can apply.

It may have been easier for some carers in particular to convey disappointment in their contact with a social worker, and on reflection more words or at least as many were probably spent doing so than giving positive accounts. As discussed in Chapter 9, the assessment that service user participants might make of contact with a social worker may well be influenced by expectations and previous experience. It is therefore possible that former relationships with social workers impacted upon current expectations of the hospital care manager. Moreover it is likely that practitioners varied in the extent to which they tried to manage service user and carer expectations. It was found that the more articulate and confident middle-class carer participants (C06, C08, C09/10), who were probably familiar with paying for the services of professionals such as accountants and solicitors, were also more vocal in their criticism of hospital social work. Furthermore, as referred to in Chapter 3, public satisfaction as appraised in research may be influenced by factors unconnected to actual service provision (Chesterman, Bauld and Judge, 2001). For example, service user participant Stephen (U18) talked about years of negative dealings with the local council.

Undoubtedly much of hospital care management is carried out away from the user's bedside, out of earshot and back at the office. Assessment will be done in conjunction with the family and other professionals and the copious documentation necessary to obtain any service for the user will be completed on the computer. Assessment and care plan forms are supposed to be signed by the service user, but are often given to the closest relative especially when the service user is unwell. Social work activity, which may have been apparent to the user at the time, can become lost in the 'mists' of the patient pathway, as shown by the fact that a proportion of the group could not/would not recall that experience. As I observed, within the operation of hospital care management, negotiations with domiciliary and care home providers were usually conducted via email or telephone. In other words much of hospital social work is hidden from the patient. This would not be the case to such an extent as confirmed by hospital social workers regarding the service user at home, when, apart from emergencies, discussions may be held at a more

leisurely pace and necessary telephone calls can be made in the user and/or carer's presence. Indeed, those who had reviews at home or in a care home were able to talk about this more transparent activity, which is looked at further in the section below (10.5.3).

Finally in this arena of 'hide and seek' there are the countless tasks performed, probably not unique to the social work profession, often unbeknown to management that the social worker may not be able to talk about. At one extreme, the physiotherapists in the focus group for this study spoke of social workers employing stalling tactics to delay discharge as a current example. Unfortunately I did not discuss with the social workers if they accepted this assertion and if so, what their motives for such 'stalling tactics' would have been. A British Association of Social Workers study referred to by McLeod and Bywaters (2000) found "covert" follow up by hospital social workers. Taking a patient to visit a family member is another task I heard about which was not strictly within the care manager's remit and may not have been known to the line manager. The undocumented good-will contributions of health and social care staff who are usually but not exclusively female, from off-duty professionals telephoning to check service users' well being to domiciliary care staff taking users' washing home and bringing them home-cooked meals 'out of hours', are well known examples of hidden social care. The latter is a topic in its own right, with similarities to consideration of the even greater contribution of unpaid carers and is looked at again as a possible area for further research in the next chapter.

10.2.3 Lack of recall

An important study outcome was that just over 50% of users were not able to remember their social worker or which staff they had contact with, confirming the findings of previous studies. It is difficult to draw conclusions from this aspect of the study, as one has to ask whether lack of recall was due to one or more of the following:

- a) The effect of their ill health
- b) The number of different professionals involved with hospital discharge
- c) The social work intervention was not in itself memorable
- d) It was seen as stigmatising?
- e) The social workers did not introduce themselves or their name and title may not have been heard or remembered.

As was previously noted, if social workers are using the title 'care manager' this is not a term that many users and carers may be familiar with. It could also be a source of confusion as 'care manager' is used to denote grades in nursing, domiciliary and institutional care settings. From the staff focus group data, the social workers seemed to be not the only professional grouping to have their identity mistaken, with physiotherapists and occupational therapists having similar problems in spite of their uniforms. These points were previously discussed in Chapter 3 in relation to other literature (Manthorpe et al, 2008). It would have been interesting to know how the non-uniformed discharge liaison sisters fared in this respect. In fact two service users (UO1 and CO3) referred to the discharge liaison role in the interviews and they did seem somewhat mystified by the title and it's responsibilities.

10.3 The main policy implications of study findings

10.3.1 Effects of fast patient turnover

It was clear that a rushed discharge or lack of notice of the discharge date had, at the very least, upset the equilibrium of a few patients in the study, coupled with anxiety for some about moving on as discussed in Chapter 7. Nevertheless, none of the service users indicated awareness of delayed discharge legislation, or the threat of fines for the local authority, affecting their hospital stay, although three of the relatives did refer to this. In their feedback session social workers welcomed such sparing of service users from the bureaucratic minutiae of social policy. However, it could be argued that the older people and/or their families had a right to know what was at least in part driving the hurried activity to discharge them from hospital. The legislation was after all supposedly enacted to benefit older people unduly delayed in hospital and those awaiting admission. The lack of information about the policy meant that little opportunity was given to aid understanding of how and why the system worked in the way it did and to comment upon process and outcomes.

None of the service users complained about a lack of involvement in their discharge plans, and the closest most of them came to participation in this respect was via their families. For those users with the biggest life changes, the study interviews took place within an institution that was not their home, which may well have minimised open critical commentary. In addition these service users came from a generation who recalled the founding of the NHS with gratitude, who might not question authority or demand the right of involvement (Wilson, 1995).

The voluntary sector discharge support team expressed a view (see Appendix 11) that older people were not given the opportunity, as they used to be in the past, for 'reassurance' in hospital by social workers, or anyone else. This was partly because patients remained in hospital for shorter periods. Furthermore they told me that the threshold of referrals had been raised, with older people diverted to their after-care service who would previously have been the responsibility of the social work department. They were also concerned about older people falling through the 'safety net', or being discharged prior to having an assessment by any social care agency. For less articulate patients, for those who do not have English as their first language, and for those with sensory impairment, one can only hope that professionals in the hospital environment would make extra efforts to ensure appropriate referrals for social care assessment are made.

There are other points that need stating, notably the fast turnover of patients enables more people to be admitted and treated. This is also a 'multiple edged sword' as older people admitted to hospital are at risk of acquired infections such as MRSA and *clostridium difficile*, the latter apparently responsible for 90 deaths at a Kent hospital in 2007 (CHAI, 2007b). The longer the in-patient period presumably the greater the risk there is of exposure to these infections. Paradoxically however the rapid re-use of hospital beds may also inhibit their proper cleaning in-between patients (Fielden, 2007) as noted in Chapter 2.

Finally, I asked the voluntary sector discharge support team their opinion of the finding from professionals focus groups that older patients' relatives had increasing expectations of their functioning and of the services available post discharge. A contributor from the Age Concern team (in Appendix 11) pointed out that it was doctors and other health professionals who had the highest expectations that patients would be able to cope following discharge! This is included as one of the contradictory issues, or tensions, faced by social workers and older service users and carers in the discussion in 10.6 below.

10.3.2 Delayed discharge legislation

Since the study began the emphasis seems to have changed from delayed discharge per se, to *prevention* of hospital admissions (DH, 2006; DH, 2005). Choice, person centred care, and personalised budgets are now the focus.

The impression is given that the legislation has done its job, that reimbursement has succeeded in the acute sector, or that is the message to be conveyed (Henwood, 2006). Furthermore, DH commissioned research studies have called for its repeal (Hubbard et al, 2008). Nevertheless, there has been policy discussion to look at the possible application of similar legislation to mental health discharges (Lewis and Glasby, 2006; Samuel, 2006). The former Healthcare Commission's annual review of health provision changed to a more complex assessment of quality measures; although reduction in the level of "delayed transfers of care" is still a performance indicator for PCTs (CHAI, 2007a) and local authorities, carried out by the Care Quality Commission 2009 -10 onwards.

There have been indications of delayed discharges rising again (Jasinarachchi, et al, 2009; Moore, 2007), with the tackling of less complex situations and delays attributable to social services. Moreover following the banking crisis and credit problems from 2008, uncertain future public expenditure on both local authority services and the NHS may affect resources for hospital and post discharge care. In 2006 it was suggested some financially challenged acute trusts had been recouping fines from local authorities in order to raise revenue (www.publicfinance.co.uk, 2006.). Furthermore there is evidence that nurses and therapists reported being unhappy with constant pressure for speedy discharges (Nolan, 2007). Age Concern nationally has criticised the latter where it occurs before older people are fit enough (Lishman, 2006) and an increase in re-admissions for some groups of older patients has been noted (CSCI, NAO and CHAI, 2006). In other words the effects of reimbursement continued to be felt and these may widen or worsen if other sectors are included. Older people will be disproportionately implicated because of their representation in mental health and other provision.

While it was clear that there had been increased spending on the provision of post discharge 'step-down' facilities, this was long overdue and could have happened without being attached to the measures of the Delayed Discharges Act (Great Britain, 2003. *op.cit*), which were outlined in Chapter 2. Although fast turnover of patients might in itself have lead to increased strain on the system of joint working, impacting upon relationships between staff groupings within the hospital, it seemed that the singling out of social services for fault has done little to alleviate such strain in the study hospital. The effect of the current legislation upon inter-professional activity in the hospital is further explored below (10.4.2).

10.4 Practice implications of study finding

10.4.1 The health professionals' view of hospital social work

As reported in the staff findings in Chapter 9, the views that other professionals had of the service provided by hospital social worker were mixed. Individual social workers were spoken of enthusiastically as were the 'good old days' of one social worker per ward who, according to a doctor, knew more about the patients than they did. Having to relate to a larger number of social workers both in the hospital team and from the community teams was clearly not popular. A physiotherapist for example spoke of strained telephone conversations with another nearby local authority social services.

'Keeping things moving' and 'oiling the wheels' of discharge seemed to be what other professionals valued most from their social work colleagues. A doctor did refer to a very positive picture of social services working on wards in the 'old days'. I was expecting to hear even hints of recent acts of social work practice that were unique to the profession, but were given no examples to present. This was disappointing given the service users somewhat brief or non-existent references to social work input. To be fair however, I did not specifically ask other professionals in the hospital for examples of social work's role in terms of relationships with patients. What was striking, albeit during brief glimpses of conversation in the context of discharge, was that social work was spoken about almost solely in terms of its contribution to the smooth running of the process. Little mention was made of professional support to patients, which may be a reflection of a reality in which this has had to decrease, as the social workers indicated.

10.4.2 Inter-professional working

It is hard to assess exactly how effective inter-professional working was for older patients, the main finding being that success varied from ward to ward. It is hoped that the effects of reimbursement upon seemingly strained staff relationships will lessen over time, although budgetary problems afflicting NHS trusts may not have helped. On the positive side, staff did give the impression of working closely together on discharges with an interchange of roles between occupational therapists and social workers, the social workers and discharge liaison nurses, and between discharge liaison nurses and occupational therapists. The nurses or OTs were most likely to take on a co-ordination role according to doctors in that focus group. Clinicians came in for most criticism from other health professionals in the

study. Their assessments were directed at doctors' power, which was said to be used to the detriment of older patients well being, specifically in relation to the timing of discharge and, on occasion, in the way that information was conveyed to patients.

Inter-professional tension

There was little doubt that there was a level of inter-professional tension surrounding the discharge of older patients from hospital, which according to the medical and nursing staff and social workers in the focus groups had been exacerbated by reimbursement. That such tensions have been longstanding within the NHS has provided a source for much comment and debate (e.g. Cornes and Clough, 2004). However Stake cautions accepting at face value data that compares past with present if data was not *generated* during that bygone era (Stake, 1995). All groups reported that they were under increased pressure from administrative tasks and meeting targets, and the social workers and occupational therapists expressed dissatisfaction with a perceived trend of threats to their client centred approach.

Not one professional in the study indicated directly or indirectly that reimbursement had aided partnership working. While this was a single hospital, this does confirm findings of the most recent comprehensive research (Hubbard et al, 2008) but contradicts findings from another contemporary study (Baumann et al, 2008), and past national research (CSCI, 2005; CSCI, 2004a). However in the case of the CSCI studies (2004a and 2005) that may be due to the level that respondents occupied within the hospitals looked at, managers possibly having a different opinion to the staff on the ground who participated in this study. Even so, there are clear implications for the consideration of the extension of the reimbursement policy to non-acute activity, a further contentious issue (Lewis and Glasby, 2006).

10.4.3 Social model of care

Despite reassurances from the doctors interviewed for the study that the psychosocial aspects of health care were of the utmost importance, if not *the* most important consideration, especially in assessment of functioning and in rehabilitation post discharge; occupational therapists and social workers were less positive about the prominence of the social model in the hospital: "Its still this very medical model, not interested in the social situation" an occupational therapist commented. In adult social care the difficulty health staff have in applying a social model and the

dominance of health approaches were officially recognised in a progress review 'Modernising Adult Social Care' (DH, 2007b). The report does focus on hospital discharge or hospitals *per se*, but does refer to the problems generated by the Fair Access to Care legislation. The latter has been criticised for some time in its emphasis on targeting services on the most dependent to the detriment of preventative work and to provision of so-called 'lower levels' of care thereby denying groups of older and disabled people access to much needed services.

The progress review (DH, 2007b) also points out that the White paper (DH, 2006) suggests a possible change of role for social workers from care management to brokerage or 'navigation' to support users in their own commissioning of care and employment of direct payments. The social workers in the study hospital commented on these changes after they were first mooted in the White Paper (DH, 2006), and were extremely critical of both new job titles and roles. They felt that the profession was already a 'laughing stock' and the subject of much confusion particularly for older people having to adapt to the title and role of 'care manager'. Indeed as discussed earlier in the chapter, the use of the latter name was seen as being responsible for older service users' lack of recognition and recall of the social work input they had received in preparing for discharge. Another possible shift for them to become 'care navigators' was greeted with dismay in the discussion group.

10.5 The study findings regarding social work and users/carers

The needs generated by older service users' hospital admission and discharge presented in Chapters 7-9 included those resulting from the trauma of ill health, relocation, and bereavement, and the decision-making that subsequently ensued, which had far reaching implications for them. However as discussed in Chapter 9, the evidence from the study findings on the meeting of these needs was uncertain. That is not to say that individuals and their families complained that they were suffering unduly, they spoke of doing their best within their own resources, to manage. Neither did they seem to have expectations that outsiders would assist them, other than in crucial practical ways. Again these were for the most part users and carers who did not have additional difficulties with communication or dysfunctional families – most relatives of users were very supportive of each other as far as it was possible to tell. Many older service users were resigned to their new situation of declining independence and did not seem to expect any further assistance with coping. In general they impressed as being satisfied with little.

Social workers also recognised that they could only 'skim the surface' of these areas with the limited time and resources at their disposal. This study's findings therefore confirm those of its predecessors (e.g. Phillips and Waterson, 2002; Rachman, 1995). I did wonder if the social workers were preoccupied with meeting the needs of those *excluded* from this study, such as people with dementia, and those from difficult situations of family conflict, breakdown and so forth, who had not been referred for potential inclusion. The hospital social workers had also indicated that these problematic examples from their caseloads, not surprisingly, took up a great deal of their time.

Issues that were particularly valued by the users and carers can be summarised as follows:

- A social worker's manner including sensitivity and approachability
- Social worker's availability
- Being treated as an individual
- Sharing of knowledge and information
- Support for carers
- Continuity of practitioner care

Most of the aspects of social work valued by recipients in this study concern process rather than outcomes, and this supports one of the central planks of the paper regarding social work roles and tasks prepared for the GSCC debate about the nature of social work (Blewett, Lewis and Tunstill, 2007) Furthermore evidence for the enquiry from users who:

'.... place an emphasis on the benefits of the relationship and the range of support activities offered by good practitioners. The role of the social worker as assessor and referrer are in fact the aspects of social work practice which adult service users seem to find most problematic.' (Beresford, 2007b: 42)

As the paper goes on to comment, the only social work role that many adults experience is that of assessor and referrer. This was certainly the case for most of the older service users in my study and neither they nor the carer participants mentioned assessment as such, although one user (U04) talked about the experience of being assessed as looked at in Chapter 9 (9.2.1). Hence this does not feature here as an experience valued by user or carer participants.

Recent research on older people's opinions of social workers across ten sites involving 1,839 participants in England reported interesting findings (Manthorpe et al, 2008). They found that 'unhelpful attitudes' regarding lack of services and being careful with the 'council's money' (p1140) as well as 'poor assessments, offering inappropriate advice and making false promises' (p1141) indicated that 'expectations of a personal relationship with the social worker being 'on the side' of the older person were unmet' (p1144). Reports of 'lack of concern, limited empathy and little understanding of the effects of disability' (p1141) were particularly worrying. An absence of a tradition of local authorities 'reaching out to older people' (p1140), perhaps because of fear of not being able to meet needs, and councils' performance being assessed on speed of response times and assessments were discussed as relevant issues here. The paper concludes with highlighting a complex level of work with older people facing often ill equipped social work teams (p1146). In an opening summary however there is a constructive phrasing of what it is that older people desire and need from social workers, which is particularly relevant to the next section of this chapter:

'It will suggest that some of the frustrations expressed by social workers about the tensions between managerialist agendas and the values of their profession are reflected in the experiences of service users. In addition it shows that older people value encounters that go beyond the simple provision of information but are rooted in empathic and knowledgeable engagement with the concerns of individual older people and their carers.'

(Manthorpe et al, 2008: 1134)

Having considered stakeholders' perspectives, I now turn to implications for the practice of hospital social work.

10.6 Tensions in performing hospital social work

I would argue that hospital social work is subject not only to the tensions that beset the whole profession, marrying the 'strait jacket' of formal assessment procedures and limited resources with individual need for example, but also to additional tensions that are unique to the setting. Similar tensions in the hospital social worker's daily round have also been described as *balancing* needs (Bradley and Manthorpe, 2000). Karen Postle in her paper expressed the concept of care managers facing both 'ambiguities and tensions' (2002:335), summarised in the box below Figure 10.1.

Postle's five tensions/ambiguities for social work

1. 'Restricted resources to meet needs: emphasis on assessment of needs'
2. 'Focusing on the minutiae of financial assessments: dealing with the person'
3. 'Spending time on paperwork and IT: taking time to develop a relationship'
4. 'Increasingly complex work: more reductionist processes such as checklists'
5. 'Concern about all aspects of risk: speed of work throughput increasing risk.'

(Postle, 2002: 340-344)

Figure 10.1 Postle's tensions in social work practice

In interpreting the findings of her own study on the experiences of care managers in two community teams Postle refers back to NISW research on the social care workforce (Balloch, Pahl and McLean, 1998). The authors of the latter wrote similarly of 'conflicting demands' and of 'role ambiguity' although some years later with a different administration in government, I would argue that 'uncertainty about the scope of the job' (p7) has probably reduced with regard to current care management practice with adults. The Fair Access to Care guidance (DH, 2002b) coupled with the Single Assessment Process has drastically curtailed such 'scope' let alone creativity for my study's social work team. Furthermore other professionals and the public in particular, unaware of such policy and procedural constraints, may still reasonably request services from the social worker, which cannot be supplied.

Tensions 1 and 2 in Table 10.1 below appertain to hospital discharge, but Postle's 'tensions 2 and 3' (Fig 10.1.) are also about spending more time on administration and paperwork than on face-to-face contact and relationship formation. Her 'tension 4', which is about managing complex work 'with increasingly reductionist tools and processes', is an interesting theme that I had not found in my data. It could well apply to performance of tasks by hospital social workers but unlike their counterparts in Postle's area teams, the former had to undertake all initial assessments whether or not more complex care management was likely to be the outcome. However her '5th tension' regarding handling of risk seems to focus on the tension created for social workers and users - whose self determination might be at stake - but is again about how best to cope with users at risk with increased throughput of cases for her teams. There was strong feeling amongst the hospital social work team in my study that risk management could adversely affect user choice. They gave examples of health staff being concerned for individual risk to the

extent that plans for 'safe' discharges were sometimes made without consulting the patient, and in this there may have been disagreement with relatives who tend to be more cautious than they were in favour of increasing independence for the user (Lymbery, 2006).

Development of a model for hospital social work

The model outlined below builds upon and extends Postle's work. It shows tensions of particular relevance to multidisciplinary practice such as the need or requirement for social workers to identify with assessments and discharge planning that emphasises service users' *problems*, rather than in the promotion of the social model of care. I would further suggest that there are tensions that can be viewed as issues that are shared with users and carers, as in Table 10.1 showing tensions and the focus of the key players interacting with hospital social workers.

Table 10.1 Tensions in hospital social work, showing origins or focus

NHS/LA Focus	User/Carer Focus	Social Work Focus
(1) Hospital system-discharge procedures etc	Individual need Carer need User/carers expectation	Social work support of users and carers Care management Professional expectations
(2) Turnover	Forming relationships	Forming relationships
(3) Multidisciplinary team [MDT]	Recovery/rehabilitation	Promoting social model (4) advocacy
(5) Information for DH etc	Information on services	Information for assessment
Social policies	User/carers involvement	Lack of time
Administration	Face to face contact	Face to face contacts
Resource availability	User choice	Resources to meet need
Risk minimisation	User self determination	Risk management
Performance management	User/carers organisations	Challenging the system

The main tensions relating to Table 10.1 above, particularly relevant to modern day hospital social work and found in the data can be grouped into five broad areas:

Tension 1: The demands of the hospital system versus individual need

A user and two carer participants (U04, C03 and C11) explained how they felt de-personalised or 'just a number' within the hospital. Two others, Harry and Lydia (U10 and C6), spoke about the requirements of the discharge process or the

'hospital system' in relation to having to leave and finding a care home place quickly for Harry and similar distress felt by another patient on the ward. An OT referred to a lack of attention to individual needs regarding readiness for discharge and the disregard for those who found moving on difficult. Social workers talked about the specific detrimental effect of delayed discharge legislation upon their work with users in different situations. It seemed to be a struggle for them to obtain even a few hours longer for patients to remain on the wards for specific reasons. There was also an example of this I found in my field notes of a social worker who tried to persuade a ward to retain an older patient in hospital longer pending alternative accommodation but failed. The woman in question was apparently at risk from an abusive partner at home. However this is not only about the needs of individual patients as these may impinge upon the needs of partners' or wider family. I have considered the position of Zena (CO1) for example, a daughter in her 70's with an older husband who felt she did not have the resources to care for her Mother Flo (U02) following her discharge from hospital (see 7.5). Keith (U15) was having a more difficult struggle after he suffered a stroke, being himself the carer of his wife, who had dementia. The social worker had to try to meet both their needs for a different type of care post-discharge.

Tension 2: Rapid patient turnover versus forming relationships

This problematic area was looked at in more detail regarding social workers and other professionals in 9.6.2 above. Social workers reported assessing older patients that they had not been able to meet face to face.

For their part, some of the user and carer participants gave the impression of *not* having formed productive relationships with their social worker, because from their perspectives the contact had been fairly minimal. The social workers and other professionals also discussed how the speedier treatment of patients, and shortage of time there was to spend with them as a result, was impacting upon their ability to form relationships and to become familiar with patients as people. This was additionally raised as adversely affecting job satisfaction in the hospital.

Tension 3: Multidisciplinary working versus promotion of the social model

Social workers conveyed a sense of being notionally part of the wider inter-professional team yet often 'left out of the loop' altogether or asked for input at the 'last minute'. When they were included it was then hard for social workers to broaden the focus of the team from purely consideration of 'medical' conditions of

the patients. This tension should perhaps be expressed as a continuum because I had the impression that some social workers identified to a greater extent than others with health professionals.

An OT complained about the absence of a social model in the operation of discharge. The social workers concurred although one of them talked about other professionals being mistaken for social workers during assessments:

S/W 2: “And the duplication in assessment – you’re aware that they’ve probably seen someone else, they often think it’s the social worker and it’s the OT or discharge liaison, and the nurses have done their assessment.

S/W 4: That might be a good thing as that might indicate people are broadening their professional boundaries into our territory and having a wider appreciation of the social context.”

However the latter comment was made to a ripple of laughter within the group, and might have been spoken ‘with tongue in cheek’.

The operation of the social model is further discussed under 10.4.2 above and is an aspect of the next closely related tension.

Tension 4: Close co-operation with health versus advocacy

In the focus group discussion, social workers spoke of not liking “conflict” but needing to be “assertive” and “confident”, placing the service user at the forefront of their dealings or negotiations with health staff. Nevertheless it must be extremely difficult to remain a trusted ‘team player’ in the multidisciplinary group while advocating for the patient, particularly around contentious issues, as described by a few of the social workers. I would argue that the very term ‘multidisciplinary’ is a misnomer. The so-called team is experienced by the social worker very often as social care ‘grafted’ onto the forum for health disciplines or health versus social services - “us and them” as a doctor participant put it. In this environment, the single social worker can feel relatively powerless. Delayed discharge legislation has determined that one group of patients who are waiting for services, still occupying a bed, are the ‘responsibility’ of social services. Social work participants referred to a negative attitude towards those awaiting services for long periods on the wards and other research has identified a loss of interest from nursing staff in older patients assessed as requiring residential or nursing care (Phillips and Waterson, 2002:183).

Tension 5: Information gathering on behalf of the agency AND user/carer information need

In the hospital setting patients require medical information about their condition and how to speed or maintain recovery in addition to social care knowledge about post-discharge services. Social workers may have a role in explaining medical information to users and carers or advocating for them to receive clarification from health personnel (McLeod and Bywaters, 2000). At the same time hospital social workers have to collect personal details about users as part of their assessment. This has been discussed in the previous chapter under 9.7.3.

While most service users and their carers said that they did not have a problem with giving information about themselves for assessment purposes, social workers found gathering this and ensuring that all relevant forms were filled in to be burdensome on the whole, especially when it had to be done within tight timescales. This may also be expressed in terms of a continuum as it was apparent that some social workers found administration and associated computer technology easier than others; equally some seemed more committed or at ease with their role as dispensers of information. Carer participants, including Lydia (C06) and Teresa's daughter (C09), reported that knowledge of services they had gleaned was inadequate, particularly in Teresa's case when she returned home from hospital with a complex care package. Fortunately there were relatives involved in both these situations that were articulate and able to make telephone calls on the service user's behalf.

Other tensions

Clearly the rest of the points listed in Table 10.1 above could apply to social work in general, although **time pressures**, given the legislative requirements around delayed discharge, and lack of **user involvement** particularly impact on hospital social work. The need to undertake **risk management** following an episode of user's ill health can clearly also be pertinent to the hospital setting and was discussed above. **Expectations** of patients and their families of the older service user's physical recovery and ability to manage at home following discharge were sometimes unrealistic were also discussed in Chapter 9. It can be part of the social work role to manage these expectations in conjunction with users and carers. However the ever-quickenning pace of discharge as discussed above can result in unrealistic *professional* expectations resulting in speedy discharges, anxiety for the older service user, even re-admissions as reported in Chapters 8 and 9.

Further reflections

On reflection 'balancing needs' or 'reconciling tensions' implies that the social worker is faced with two opposite positions or conflicting demands. In essence, as this study has shown, it is arguably more complex than that. I suggest that the 'balancing' or 'reconciling' is more akin to the actions of a juggler attempting to keep several items 'in the air', while responding to pressures from different directions, albeit the juggler's skill is usually for the purpose of entertainment. The metaphor is also oft used in relation to women and particularly regarding working mothers or carers who have multiple competing demands upon their time. Figure 10.2 below is a diagrammatic representation of the social worker engaged in negotiating issues with users and carers against a background of multiple demands.

In the diagram, Figure 10.2 the outer fragmented circle represents the external milieu in which the relationship between service user/and or their carer and the allocated social worker operate, the arrows indicating impact upon that relationship. Inevitably for the sake of reducing complexity, symbolic diagrammatic representation can give the impression that something is simple or straightforward in real life, when the opposite may pertain. The institution of the local authority does provide support mechanisms in the form of supervision and peer support, and social networks can equally provide comfort and productive relationships for service users. For the individual, both worker and user have personal and professional ethics and values that they bring in addition to their personal characteristics of gender, race, and income.

Pressures and Tensions for Hospital Social Work

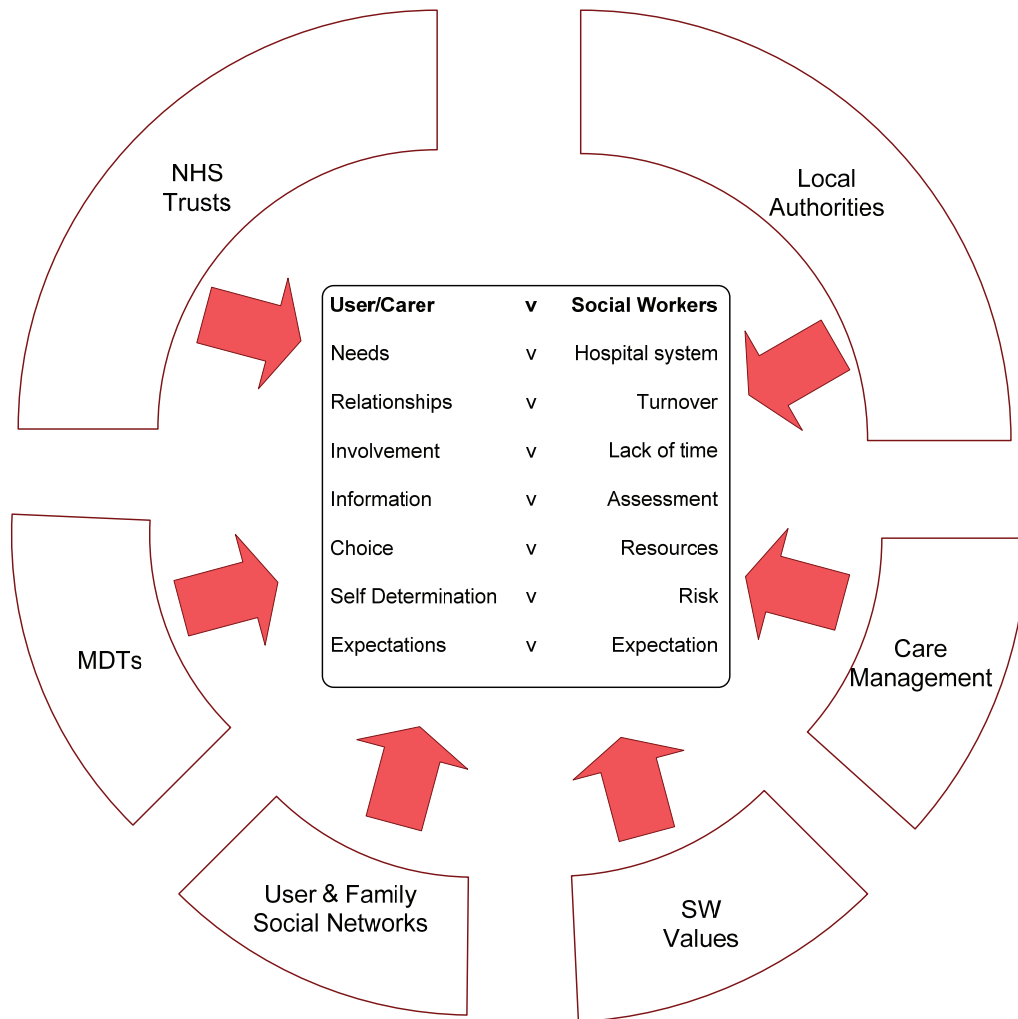


Figure 10.2: Pressures & tensions for hospital social work

MDT = Multidisciplinary team working with older people in hospitals such as the one upon which the study was based.

What can social workers do to find a way through the chaos and reconcile these tensions? It has been shown that in itself facing and dealing with perpetual tensions at work as outlined above can cause stress (Balloch, Pahl and McLean, 1998). Postle looks to social work training to prepare future practitioners and for 'broader approaches' to work 'within communities and across teams and networks' (Postle, 2002:346). In examining the shared issues between social workers and user/carers, there are common causes for both parties to unite and form alliances as has often been called for (e.g. Dominelli, 2004). The question is whether in a hospital establishment with social workers effectively facing two dominant hierarchies of the NHS and local government, how feasible that is and particularly uniting with frailer older people who may be oppressed further by disability, race, class, gender, religion or sexual orientation. Nevertheless as has been argued by Foucault (Rabinow, 1984) and others, where power is located there is resistance, and so I returned to the data to find examples of positive steps social workers felt they were taking, no matter how small or insignificant. The essence of what they said they were able to achieve, not always and perhaps not often, is presented in the phenomenography Figure 10.3 below.

<p><i>Informing care management with social work</i></p> <p><i>Holism-seeing the whole person</i></p> <p><i>Being confident and assertive with other professionals</i></p> <p><i>Building and maintaining relationships with users and carers where possible, in spite of the 'paperwork':</i></p> <ul style="list-style-type: none"> • <i>Being kind</i> • <i>Being there, spending time when you can</i> • <i>Being a 'name' to contact</i> • <i>Putting 'the relationship' at the forefront</i> <p><i>Prompting and questioning re: consultation with patients, with the multi-disciplinary team.</i></p> <p><i>Taking risks with risky situations where it is user choice.</i></p> <p><i>Discussing oppressive practices with management and Health.</i></p>

Figure 10.3 Phenomenography of social workers' reflections on their positive contribution to the discharge process

10.7 Hospital social work and theoretical models of practice

As detailed in Chapter 1, the most popular and enduring model of social work practice has probably been Payne's triad of therapeutic, administrative and transformative ways of working (Payne, 1991). As has been suggested the most effective practice may contain all three elements (Lymbery, 2005). The study interview data **uncovered** only the administrative form of social work although it is possible that the social workers were able to conduct some therapeutic type practice when they had the opportunity, with non-participants of this study for example, but this by their own admission seemed to be relatively rare or it was hidden or unofficial. This lack of recourse to counselling or therapeutic skills is in contrast to the reports from social workers who took part in a post community care study (Bradley and Manthorpe, 2000) which supported the contention that counselling skills are more likely to be used by social workers in hospital than community settings (Scrutton, 1999).

In multidisciplinary meetings, and in their advocating on patients behalf, there may have been some social work activity that could be classed as collectivist or transformational. Certainly from the social workers' conversations in the team room, they indicated that they had to adopt some challenging approaches, such as arguing for a discharge to be delayed for social reasons (e.g. U12); but this seemed to depend on the personality of the worker and on whether the advocating or challenging took place as an individual exchange or at a ward meeting. The extent to which a social worker could challenge or advocate on behalf of a patient in a ward meeting in turn apparently depended on which professionals were assembled together and the dynamics of that particular gathering. For example if there was a particularly vociferous ward manager, discharge liaison sister or consultant present, and/or large numbers of other professionals, which seldom would apply to social work or even social care, those factors could influence the whole tenor of the proceedings and a social worker's willingness to argue, challenge or present an alternative from a social work perspective. It would have been interesting to observe some inter-professional planning meetings for this purpose.

10.7.1 Link with debate on social work's changing roles and tasks

The discussion paper on social work roles and tasks prepared for the DH/GSCC sponsored debate about the nature of 21st century social work (Blewett, Lewis and Tunstill, 2007) is referred to briefly in the literature review, since it was published after completion of this research. While the paper does not look at hospital social work with older people in particular, it does recognise that much needs to be done to address the public image of social work. While the authors believe that Government has a part to play here, they also see an educative role for social work with other professions. I would suggest that the delayed discharges legislation has reduced the power and status of social work in the hospital setting, which in turn has affected the image of the profession and the confidence of social workers to be equal partners with health partners, let alone be educators.

The paper (Blewett, Lewis and Tunstill, 2007) does however contain a discussion on the policy context for social work, and looks in some detail at the government's 'independence, choice and control' agenda. It criticises the emphasis on health solutions, the preoccupation with employment and neglect of human frailty, poverty and inequality, and the continued lack of resources to fund programmes. User empowerment is a key policy objective, with direct payments at the heart of social care reform. Again reservations about funding, back-up and meaningful choice for

people opting for the schemes are raised. Nevertheless it does not consider how all those older people needing social services for the first time upon leaving hospital will have direct payments, let alone personalised budgets arranged, given the shortage of time at care manager's disposal. Indeed direct payments did not figure in the study for users, carers or professionals, indeed users and carers who were asked about direct payments denied knowledge of the scheme.

The discussion paper concludes with a section on the 'key features of being a good social worker' based upon service user's experiences, which are similar to characteristics valued by this study's service user and carer participants:

- 'Someone who sees the person in a holistic way – and treats them with respect, listens to them etc
- Someone with the right personal qualities
- Someone with the capacity to use their skills to empower others, rather than be paternalistic.' (Blewett, Lewis and Tunstill, 2007: 29)

The report goes on to question whether the context within which social work is practised will allow 'good practice' as above to flourish in the future. Some older people especially those who have been physically and/or mentally devastated by illness and are in hospital at the point of discharge, may not feel ready for 'empowerment' immediately, and in fact I would estimate that the majority of user participants in this study fell into this category, such was their level of ill health, frailty or lack of confidence. Service users U02, U03, U05, U06, U07, U10, U11, U12, U14, U17 and U19 would all have struggled one way or another to be fully involved in the discussions for example. Contrasting three service users illustrates this point. Teresa (U14) and Harry (U10) both impressed as having been confident, assertive people in further education and business fields respectively, as was Gertie (U09). All three feature in the illustrative case examples (Chapter 6 and Appendix 2). However, Gertie had been in hospital longer and was probably fitter than the other two and did not have the communication difficulties of dysphasic speech to cope with as they did. She knew what she wanted and with family support achieved a place in a residential home. Teresa was perhaps more diffident and uncertain where she wanted to be, but returned home with family support. Harry told me that he knew he did not want to go to a care home but there was no alternative at that time.

10.8 Conclusion

This chapter has drawn together some of the main findings from the study and looked at methodological, policy and practice implications, locating the key issues within a theoretical framework in 10.6. The analysis of the tensions inherent in social work as identified by Postle and others has been developed to focus on the particular operation of hospital social work post-reimbursement, which may function at one extreme as a type of discharge planning. The model has also been widened to incorporate a user/carer perspective in the context of institutions and wider society. As such it is suggested that this re-worked model is a contribution to knowledge. The concept of hidden or invisible social work has also been raised in relation to methodology and will be looked at further in Chapter 11. This chapter has additionally updated links with policy and practice debates. The potential for improving practice within a hospital setting is discussed in Chapter 11.

One of the key messages from the policy implications section above is that the enactment of delayed discharges legislation was not aiding already tense inter-professional relationships in the study hospital. Furthermore the insistence that partnership working is the only way that discharge can be effectively planned and managed for older patients (DH, 2005) is questioned. Given that health and social care are unequal partners in the hospital setting, looking at the evidence from the study there is the risk that where a medical model predominates older people do not receive psychosocial or social care support when and where it is required. Clearly while co-ordination and communication are absolutely vital in setting up and operating post discharge services, older people's psychosocial needs may be better served by that 'someone who is apart' (SSI, 1993), as a service user participating in a previous review put it.

Apart from the doctors, professionals in the focus groups spoke of the struggle keeping pace with the sheer volume of patients. Short stays with speedy discharges and transfers to short term accommodation did not suit some of the older service users either. Perhaps the fast turnover of patients minimised the chances of obtaining hospital-acquired infections and meant that other patients could be admitted with less time to wait. Again the latter is not as encouraging as it might sound as the number of beds has declined in the last decade while the population of over 75's has grown. It seems that while older people may be treated outside of the

hospital system, supervised at home by community matrons or in a separate intermediate care settings, benefits for them remain uncertain (Mulley, 2006).

The next chapter will look at the study's scope and investigate how far aims and objectives were achieved, before turning to further areas for research and the final conclusions.

11 Conclusion to the thesis

11.1 Introduction

Following on from the broad and specific implications of the research findings explored in Chapter 10, this final chapter begins by considering the study's scope, its contribution to knowledge or uniqueness and the achievement of research aims. Before presenting these reflections, it is perhaps useful here to restate those research study aims:

- To explore how older people leaving hospital and their carers experienced the discharge process, focusing particularly on social work activity;
- To examine how social work operates within the care management model in hospital in the context of the discharge of older patients;
- To investigate the effects of the Delayed Discharges legislation or reimbursement, upon service users, carers, the professionals and their work, in the study hospital between 2004-6.

Fuller details of these project areas can be found at 1.3.

This chapter will then locate the study in the context of previous work and draw out some of the key themes that emerged from the data before looking ahead to future research. The findings have also raised some questions and areas that merit investigation in their own right. The chapter and the thesis conclude by returning to social work practice, identifying some fundamental issues and with suggestions for improvement in hospital social work.

11.2 Review of research design

11.2.1 Philosophical approach and user involvement

Phenomenology was the guiding approach underpinning the study and as explained in the Methodology chapter (4) this was governed by pragmatism and reflexivity rather than being about 'rigid restrictive method' (Hallett, 1995:55). I have therefore

aimed to follow the work of nursing researchers and indeed a piece of research on hospital discharges for older people (Stanley, Reed and Brown, 1999). In the previous chapter I discussed some of the inherent difficulties in utilising and adapting the methodology. A phenomenological approach also demands 'bracketing out' of the researcher's pre-conceived or sub-conscious influences upon their work. As discussed in Chapter 4 the ability of researchers as human beings to rid themselves fully of deeply held assumptions is questionable (Poindexter, 2003). In interpretation of the data, one has to carefully search for and make sense of the meanings of common themes to suggest explanations and rival explanations. To leave the data at the level of pure description is unsatisfactory in constructing a thesis (Wolcott, 2001).

Regarding the work of others and older people's involvement with the process of the research, there has been interesting work carried out with older people in *all* stages of a project including design and data gathering (Clough et al, 2006). There are different models that have been developed, depending on the type of investigation and circumstances, not all would be suited to a PhD framework. To go some way towards achieving greater service user involvement in research, some academic researchers have established steering groups in collaboration with organisations such as Age Concern or Older Peoples Forums (e.g. Bywaters, McLeod and Richards, 2005). To consider how this model might be adapted: firstly, the number of members in a group would need careful thought as over a period of three years or more this could dwindle due to poor health or caring responsibilities for example. Preparation would need to include: training, attention to ethical issues such as confidentiality - as in any research project - transport and payment of expenses together with other rewards or benefit for those attending. In increasing direct user involvement in a study of this type i.e. the potentially sensitive topic area with participants who by definition had recently been ill, the researcher has to be mindful of their needs in these circumstances.

Perhaps the greatest test to apply to my study, linked fundamentally to the research aims, is whether I have represented service user and carers' views fairly and truthfully. By this I am aware that the interview was a subjective social construct between two parties, the interviewer more powerful than the participants and influenced by the context. There are other participants' rights to bear in mind, most notably the social workers with whom I spent most time in comparison with the other professionals in the study. Without their referrals neither contact with user

participants or the individual interviews could have been arranged. Some user participants as reported were adamant that they did not want to criticise the NHS in particular. There is one example I can refer to of Mona's (U03) aside that everyone seemed to know about the plans for her future, but she had not discussed these directly with them. This was said after making a statement, in her hospital room, that everyone and everything that had occurred within that institution had been positive. Listening to her tone of voice I believed at the time there was a slight nuance there that she had felt excluded from decision making but when I asked her directly about this she replied that staff were only taking care of her and acting in her best interests (see 8.5.2.).

11.2.2 Methods selected

The use of semi-structured interviews seemed to work well as a tool for generating data from older people post discharge, as discussed in Chapter 5. An unstructured interview may have worked for some but not all the older people would have been comfortable as most of them started our sessions with: 'well what do you want to know?' Had I been able to spend longer with the older service user participants, and developed a deeper relationship with them, had I been able to immerse myself in a residential setting for example, as some other researchers have successfully done (e.g. Cook, 2007), they may have disclosed to me their personal experiences of discharge more fully.

Another method for increasing the scope of the data would have been to use observation alongside interviews. I discounted observation of social work interaction with service users from the start because in my past experience as a practitioner working with students. The presence of another person can influence behaviour of the practitioner if not that of the service user, the 'Hawthorne effect'.

11.3 **The study and its predecessors: some key issues**

In the previous chapter I aimed to link the study findings with theoretical models of social work and debates current at the time of writing. I now want to explore the link between the main themes found in this study and previous relevant research. For the most part the study findings confirm those of its forerunners as indicated throughout the thesis. Most striking is probably the similar 'lack of resources and shortage of time' as found by Margaret Gregory in Nottingham 10 years previously (Gregory, 1997). These characteristics of social work and social care provision were manifest in the lack of choice and availability of both intensive care packages

needed, care home places and time at the social workers' disposal to assess and as they acknowledged, to give support to users and carers. Some older people and their families did indeed also want 'more time for reflection and help to prepare' (Phillips and Waterson, 2002: 182) prior to discharge, only a few said they had been keen to leave hospital, usually to return to spouses or to resume a caring role. Carers were more critical of lack of help to find care home places.

Looking back, it is difficult to convey the complexity of issues in summarising attitudes of service users and their families to the discharge outcomes and transitions involved as gathered in the study data. This complexity has been acknowledged in recent literature (Hubbard et al, 2008). In SCIE's synthesis of findings (SCIE, 2006) they describe older people re-negotiating or re-drawing their own 'life plans', rather than being passive recipients of the discharge process. Others found discharge to be a stage on a journey on which older people and their carers 'travelled hopefully' neither expecting nor experiencing a 'smooth process of transition' (Phillips and Waterson, 2002: 180). There was a certain level of 'stoical resignation' (Reed and Stanley, 2000) to changed situations as discussed for this study's older respondents. Thinking about the service user participants who were discharged from hospital, they had a wide variety of opinions between them that also changed as they reflected further. Surely, variables such as race, culture, class, and gender are relevant here, I would argue. This study looks at other differences in approach between staff and users discharge, as does the SCIE review (SCIE, 2006). The authors of the latter remark that where as staff might see discharge as an endpoint, this is not the case for older patients. It is not surprising that, as I have indicated in Chapter 9, service users and their families had a range of different concerns and priorities, regarding information and support for instance.

User involvement in discharge was another key area this study set out to examine with the sample of older people in the study hospital. There was evidence of ceding of power (as raised by Myers and McDonald, 1995) to relatives as a positive step, mostly sons or daughters became their proxy representatives during assessment, care planning and decision making, notably choosing of a care home place. The majority of service users had close and trusting relationships with these family members but I am aware that this is not always the case as discussed in 11.6.4 below.

There was still uncertainty about the care management role and the identity of the care manager as found in the past (Manthorpe et al, 2008; Stanley, Reed and Brown, 1999) in addition to lack of user knowledge about the assessment which took place, another echo of the work of Phillips and Waterson (2002) and Godfrey and Moore (1996). Phillips and Waterson also queried whether social work was being conducted at all in their study location such seemed to be to them the loss of 'social' from the activity. As discussed in 10.6.1, it seemed that social workers in my study hospital were engaged for much of their day in variants of discharge planning which were at times focused on the process rather than being 'person centred'. But it was not as simple as that sounds. There was evidence to show that service user and carer participants had, from their perspective, for the most part been treated with respect and humanity, which they valued. I am also left with the hope that more support was given to the non-participants, but more than a hope because I witnessed discussions between social workers and families during telephone conversations, which did demonstrate caring and concern in intent and practice.

Returning to the discussion of hidden or 'invisible' social work as discussed above, phenomena concealed in every day life but which would be useful to make open or concrete knowledge for practitioners to learn from, have been termed 'silences' in the arena of Appreciative Inquiry. One silence explored concerns what Liz Mellish calls *shifting between two paradigms of management* - in her sense and of particular relevance to health environments - moving from a 'hierarchical' world view to a 'participant centred' one. That shift is a daily occurrence for the hospital social worker. The second relevant silence she wrote about was the '*micro strategies of large-group facilitation*' in the context of organisational change' (Mellish, 2007: 31). While applying to a different setting, such 'micro strategies' or 'craft knowledge' are perhaps what the researcher could tease out from data on social work practices. Alternatively drawing from the work of Beresford, Adshead and Croft (2006b) or Carter and Everitt,(1998) one might want to assert that it is the very 'ordinariness' of the relationships between service users and social workers that matters. Does this then become a type of professional liaison or relationship among equals for the purposes of their (social care) transactions, if not in a stratified wider society?

The following extract gives a flavour of a description of the health and social care of a dying woman who stayed at home supported by her family:

'The help she, and her carers, got was a wonderful mixture of the practical and the emotional... Eleven days before she died, a social worker visited and did a care assessment and, by that afternoon, a care package was in place. It sounds so bureaucratic, a 'care package'. But it couldn't have been more humane and person centred...' (Ferguson, 2007:3)

Ferguson continues in this personal account to give the details of the kind of care his mother received and how it was administered. What Ferguson terms here as "moral perfectionism" (Ferguson, 2007:3) a concept derived from the sociological work of Arthur Frank, (Frank, 1995) emphasises the 'care' in care management, as opposed to a managerial or 'business' perspective which focuses on management activity (Dustin, 2007).

Regarding joint working and other aspects of hospital social work I have described it in the last chapter as balancing different, sometimes contradictory issues. After writing the previous chapter I discovered that this concept or model of 'balancing' in social work has been used before in the literature (e.g. Bradley and Manthorpe, 2000). With regard to care management Postle's work on 'ambiguities and tensions' was also looked at (Postle, 2002), and a model of hospital social workers negotiating tensions between different positions whilst also subject to external pressures, was developed. For example, it is difficult for staff to promote needs led or even person centred approaches to assessment and delivery of cash limited services and operating eligibility criteria in accordance with government policies. In adult social care it has also been acknowledged in a 2007 report that health bodies and personnel have struggled to adopt a social care perspective (DH, 2007b).

11.4 Achievement of research aims

It is suggested that the main study aims as outlined at the start of the chapter have been achieved. All 19 of the service users interviewed talked about aspects of that experience for them. Carer and professional participants were able to shed more light on the social work contribution to the discharge process and the social work team spoke openly in focus discussion groups of inter-professional relationships. These group discussions yielded rich and interesting data on underlying tensions beneath what had seemed productive and outwardly harmonious relationships. Professionals were particularly vocal on the health and social care divide, on overlapping roles and on fast patient turnover, targets and administration impinging on their work with patients. It was nevertheless

disappointing that despite going to some lengths through the sampling and introductory conversations with older service users that many of them were unable to comment on the social work input to their discharge. Actual numbers recruited to the study [n=19] reached the upper level of the target sample of 15-20. Because of the time taken to recruit these service users and their relatives, 17 months, it was not feasible to recruit more participants who may or may not have had a greater capacity for recall and engagement.

The ethical objective of doing no harm to respondents was met as far as was possible to tell by taking measures described in Chapter 4 and by checking with the social workers and the reviewing officer responsible for most of the follow-up for feedback on any longer term effects of the interviews. Immediately after the session de-briefing was carried out with participants and time spent with them to monitor physical and emotional welfare. Many of the participants from all three groups said that they had enjoyed the discussions or interviews. One relative, a senior citizen herself, sent me a card thanking me for listening to her. Moreover I was able to follow up issues raised by service user and carer participants as requested, such as reporting concerns to the hospital's Patients' Experience Team manager - in accordance with the ethical stance required for social work research and by the (former) COREC process.

The key issues that pertain to the aims, objectives and research questions outlined above within the context of the study hospital, are now discussed in the broad areas of:

- Older people's experience of hospital discharge
- Perceptions of social work in the study hospital
- The effects of Delayed Discharge legislation

11.4.1 Older people's experience of hospital discharge

The following are the main issues that emerged from the themes chapters based upon data gathered from interviews with uses and carers:

Effects of separation

I believe that that the implications of loss for older people including the effects of hospital admission as reported in the study and discussed in Chapter 7 are often not fully considered. Moreover I would suggest that the long placed emphasis on

discharge could obscure or 'blunt' such deliberation. The hospital admission could mean that previously active people as described who were making important contributions found themselves suddenly having to face separation from significant others and focus purely on surviving or on activities of personal care and hygiene confined to their bed or chair and the space around it. The chapter also includes instances where users and carers have gained in practical terms from their hospital stay e.g. in receiving an assessment for first time.

Loss experienced by service users, carers and staff

Whether bearing loss as described for service users and carers was different for those who had experienced a gradual deterioration or a sudden trauma of physical health, depended upon their exact circumstances, support and personality. Likewise social workers and nurses as human beings cope with the stress of working with such loss and separation day by day in varying ways. However, aside from supervision sessions that may not happen very often and 'offloading' of emotions with team colleagues, any difficulties in coping with that continual loss are seldom acknowledged (Brearley, 1989) and did not feature in focus group discussions.

Loss of life was not looked at separately in the thesis apart from consideration of service users who were grieving for their recently departed spouses. Three carers and two service users did however talk about the effect: the preparation made by families and the shock for everyone when a patient very nearly dies, but is brought back from the brink by medical science and nursing care. Two service user participants died within three months of being interviewed and one carer who agreed to be interviewed after her Father's death spoke frankly about what he and they had been through. Given the latter deaths and the fact that five patients who were referred to the study died prior to making my initial approach, one man just as I arrived on the ward, this most significant of all losses touched me as a researcher. I do refer to the presence of death in nursing homes, but as with many staff involved in caring for sick people, I think I entered into a 'conspiracy of silence' on the subject.

Adjustment and transition

The importance of continuity of support and the difficulty for some users in adjusting to new environments and to new social workers or care managers is a re-occurring theme in this study. Some service users had faced multiple moves within or out of hospital and transitional care was not a positive choice for a few. The lack of visits

either to the care home they were going to move to or to former dwellings to say goodbye (literally and metaphorically) was discussed in Chapter 8. The position of close relatives and carers must not be forgotten as the 'conveyor belt' of discharge from hospital rolls and the attention focuses upon the user particularly when they are not returning home. The carer's role, often reduced to that of a care home visitor, is less clear.

Another point that emerged during my visits to care homes and hospital wards was the image of the older person as spectator. Due to ill health, disability or frailty, their mobility and general functioning can be impaired whilst the staff that they depend on seem to move around ward or care home faster than ever. Talking to service users about their experiences of both care homes and domiciliary care, I became aware of service quality shortfalls. For those service users who returned home with a care package issues regarding timing, length of visits and staff attitudes, both positive and negative were highlighted. An occupational therapist also raised the matter of the rapid calls she was informed that home care staff were having to make, resulting in outcomes such as decline in cooking of fresh food in favour of convenience meals heated in the microwave and less time for personal care let alone conversation with older people. The latter was missing, too, for those service users who went to care homes and found they were isolated among the sensory and cognitively impaired. Some carers talked about care home staff whose first language was not English resulting in communication difficulties for them but with some evidence of racist attitudes in these reports.

Decision making

In Chapter 9 I wrote about a doctor stating how older service users and their carers are in the possession of increased knowledge when they come into hospital now. The implication here was that people generally are better informed of their rights and about their medical conditions. On reflection, I would argue that such a generalised viewpoint can provide further reasons for retaining rather than sharing knowledge in hospital, particularly in relation to user and carer participants, there is so much more to know now. Importantly, only one user and two carers referred to browsing the Internet where there is such a vast amount of information available it can be difficult for a layperson to find reliable, trustworthy, discernible accounts.

The role of social work in decision making was minimised by some in the hospital team during our discussions and described as being under further threat from other

professions, particularly occupational therapy. The social worker's tasks in gathering information for assessment and matching available resources, then 'selling' the products to service users was seemingly not visible, understated or forgotten by the latter. Given everything else older people had to cope with during and after their hospital stay, this was nevertheless unsurprising.

Some of the study's participants, in particular two users and two carers, commented on the formality of decision-making meetings held on the hospital ward.

Nevertheless meetings to plan services were welcomed by carer participants as being helpful and informative. I suspect these events were for the most part much smaller and more informal than the case conference type meetings, without every single ward-attached professional and their students present. Home visits with a small group from the multidisciplinary team to assess for post discharge services were additionally welcomed by carers as useful and a helpful 'reality check'. For two of the users however the impression was given of a 'test' that they had to pass in order to return home, which may or may not have been about the attitude of professionals during the experience and the time they had available.

In Chapter 8 I also looked at experiences of choice and choosing care homes. I have commented that as social workers we can underestimate the crucial tasks of informing and supporting users and carers through this process. Included in the role of steering the latter through this maze has to be time devoted to ensuring their comprehension of the complex financial procedures. Then there is awareness of what to look for in a care home, that the calibre of the care staff is usually more significant to the resident than the wallpaper in the hallway for example. That is not to suggest that there is much choice available with some parts of the study town having no care home nearby. About 25% of nursing homes have closed since 2004 when delayed discharge legislation came into force, one of the factors which effectively shortened the period available to older people in hospital to locate and chose a suitable place. The financing of care home places was a big issue for participants, not always adequately addressed, and features in the recommendations at the end of this chapter.

11.4.2 Perceptions of social work in the study hospital

Given the lack of recall of user participants and the fact that the study looked principally at hospital rather than community based social work, I do not wish to compare practice in the two settings. However, users such as Gertie (U09) and

Keith (U15) had a longer association with their community social worker and it is understandable that service users will compare the interaction. Returning to the theme of 'hidden' social work briefly, I discovered on re-examination of the data a brief aside that I had missed in an interview transcript. Barbara (C03) was talking about her Father's (Eric, U05) isolation as he was bed-ridden in a nursing home:

'But at least in hospital he saw people all the time and people visited him, like the social worker, they kept in touch with him, he would say that they had been to see him.' **C03**

Eric (U04) had experienced a traumatic sequence of events – a severe stroke, discharge to a care home, followed by many re-admissions culminating in his death. Barbara was critical of some aspects of her contact with the social worker, her Father had no memory of which personnel he saw in hospital but I had initially missed this positive comment in the data.

What constitutes good practice may differ for the three groups of service user and carer participants. Gertie (U09) for example (one of case example subjects in Appendix 2) was almost dismissive of her hospital social worker and it was difficult to obtain a coherent picture of the hospital social work input to her. There were indications of good practice in the early attempts to create as much independence as possible for the service user and then promoting her right to self-determination in seeking a care home place. The hospital social worker informed me that she had conducted the placement review herself, and in doing this and organising the trial overnight stay she had done much to ensure that Gertie was content with her own decision not to return home. However Gertie gave no recognition of any positive aspects of the hospital social worker's role in our discussions. It was not possible to additionally talk to Gertie's son or daughter as they might well have had contributions to make to the study, for example, had they received assistance from the social worker in choosing a care home and regarding funding?

How service users and carers actually learned of professional opinions particularly on realistic options for post-discharge care, including the staff responsible, emerged as an important issue in the data. Teresa's (U14) family reported that they were caught completely unawares when they were told that she would probably have to move to a care home. Seemingly small incidents can have unimagined repercussions for service users. The casual 'chat' when the social worker is trying to put people at ease for example or those standard letters sent by administrators to

transfer cases to another department may hold serious, life changing meaning and implications for service users.

Increasing clarity of the social work role was given support, if not wholeheartedly, by the team in their focus group discussion. The attractions of trying to put boundaries around the role for example in not retaining responsibility for older people leaving hospital are apparent: they would be then be able to state, like their health colleagues, 'we don't do that' regarding outstanding or ongoing tasks post-discharge. The social workers were also sympathetic to the users' and carers' desire for continuity of service. I can empathise with the practitioner's predicament in wanting to contain and manage burgeoning calls upon one's time from large caseloads. However as has been pointed out, delayed discharge legislation has negatively circumscribed the hospital care management role (Lymbery, 2005). Furthermore it is performing those extra non-essential tasks, giving time and making people feel they were not 'just a number' that was valued by service users and carer participants. There is also the argument that social work operates at the blurred margins of society, of health and social care and associated professional activity, and occupying such territory is not always a comfortable position to be in.

In the conclusion to Chapter 10 (10.7) I briefly considered the future of partnership working or the desirability for it to be intensified from the social work practitioners' and service users' perspective. Given the struggle that health staff have to address the social care needs of adults (DH, 2007b), there is a danger that if social work continues to be further incorporated into health and if it becomes further imbued with evidence based, target driven strategies that the vacuum for users, left by care management will grow.

11.4.3 The effects of delayed discharge legislation

When I originally conceived of the research I was keen to find out the impact of Delayed Discharge legislation upon working practices for the professionals and on the quality of discharge as perceived by older patients. When it comes to weighing up the evidence, it was hard to tease out trends such as speedier discharges that had already started some while ago, due mostly to medical advances and the hospital trying to meet the target for maximum of 18 weeks waiting for admission. In fact the social workers talked about both targets and the Delayed Discharge legislation impacting upon their work and speed of the discharge for older people. I had also questioned whether there was less choice available to older people as a

direct result of the latter. Again the situation is too complex to reach a simple answer. Care homes had been closing for some while in the locality, but new rehabilitation and intermediate care facilities funded by the NHS had opened. Although these gave more choice of post-discharge location for older people, both resources are short-term resources rather than permanent provision for those unable to continue living independently at home. Furthermore professionals referred to the existence of such 'step-down' facilities in itself presenting an additional pressure for older people to move out of acute wards.

In the previous chapter I also make the points that there has been a shift in emphasis of government policy away from the focus upon delayed discharges to the prevention of hospital admissions and provision of treatment and care at or nearer to home as part of the personalisation agenda. Moreover consideration of research commissioned by DH suggests that the reimbursement policy has run its course and does not recommend extension of the legislation to other groups of patients in the non-acute sectors (Askham, 2008).

11.5 Social work with adults and uniqueness of the study: key issues

The study's contribution to practitioner knowledge

In the literature review I looked at many studies of hospital discharge and older people, some which included a focus on the social work role and a few since 2003 that have sought older peoples opinions of discharge (e.g. Swinkels and Mitchell, 2008) or social workers (e.g. Manthorpe et al, 2008). As stated in Chapter 3, in conducting this research I had planned to update earlier work (e.g. Phillips and Waterson, 2002) in an era of health policy change and uncertainty for the future of social work with adults. Overlaying national policy and practice developments there were also specific local issues as reported fully in Chapter 5, most notably a recent social services' reorganisation that had led to hospital social workers becoming responsible for care management, less than a year before the first study interview.

In section 11.4 above I gave an overview of the main findings in relation to service users and their carers, some of which cover unexplored territory. Older service users' and their carers' reported experiences of hospital social work provides a unique snapshot of practice in this setting at a time when reimbursement legislation was in force and potentially impacting upon the discharge process. Focus group findings give some insight regarding the effect of delayed discharge legislation upon multidisciplinary working too, as well as hospital professionals' perspectives on

social work. Furthermore users and carers' accounts of interaction with social workers are compared and in some instances focus upon aspects of practice around issues of bereavement, user involvement or communication skills for example, that are not confined to the discharge process. However, the focus on the social work role in the study hospital has given a newly developed perspective of a model of care management practice (Postle, 2002), which in addition to the discussion of 'hidden social work' in 10.2.2 referred to above, can I would argue, be seen as contributions to practitioner knowledge.

Capturing experiences of social work

Reflecting upon invisible or hidden social work looked at in 10.2.2 - the enigma that eluded the open-ended discussions that I had with user and carer participants, this was not something that I had seen described in the literature in the context of hospital social work. As a new researcher I realised that I must put aside my own previous personal experiences as a social worker but my understanding of qualitative approaches was that one's background and stance must be acknowledged recognising that it is not possible to 'cleanse' oneself of one's past as already discussed. So with reference to my own biased practitioner knowledge coupled with the uncomfortable notion following data analysis - surely there was more to this portrayal of social work than that? Hence I call for a new or different way of talking about and researching social work. Too often the published narratives of carers or relatives have focused on what has gone wrong, reflecting on poor quality services, from which lessons clearly still have to be derived, rather than pinpointing where and how it has felt 'right'. However, serious case reviews of social work practice with children and families between 2008 and 2010, together with reports on inadequate safeguarding of individual adults who are mentally ill or with learning disabilities have received a great deal of negative media attention (Siddique, 2008). A focus on mistakes that were made - even though other professionals have not escaped criticism - makes it harder for constructive appraisal of all social workers in such a climate.

11.5.1 The nature of hospital social work

Thinking about the complex portfolio of competencies required for hospital social work the starting point has to be drawing out the skills from study findings that feature in the six National Occupational Standards (TOPSS, 2004). In essence key social work competencies are:

- Effective assessment, problem-solving and care planning

- Ability to rapidly acquire holistic knowledge of the service user and their circumstances
- Broad knowledge of local social care resources, relevant financial systems and how to effectively share that information
- Assessment and management of risk, including knowledge of safeguarding or protection issues and procedures
- Advocacy
- Functioning as a member of multidisciplinary teams

Here I propose are the bare minimum of skills required. Although evidence was not available concerning the last two points on the next list, hospital social workers it can be argued would also need to demonstrate:

- Ability to build self-confidence in, and relationships with, service users and their carers often over a short period of time
- Knowledge of common medical conditions and terms
- Motivation to place service user at the forefront, despite hospital hierarchy
- Confidence in relating to other professionals
- Operational knowledge of crisis intervention and bereavement theories
- Knowledge of how ill-health impacts upon: different cultures, physical and learning disabilities, mental health including dementias.

In a nutshell a competent social worker would have the above skills at her fingertips and also have knowledge of relevant law and be able to reflect critically upon her own performance and wider links with societal institutions/policies. In addition there is the key ability to span boundaries, in particular bridging the gaps between medical/hospital related processes and the individual and between hospital and home. For example, when an adult is admitted in an emergency there may firstly be dependents back at home to take care of ranging from disabled people to children and/or pets necessitating knowledge of legislation, of accessing children and families' services, and the resources of voluntary organisations. In the last chapter I looked at the difficulties hospital social workers face in carrying out many aspects of their role for various reasons: time constraints, competing demands etc.

The question remains whether any professional or volunteer could be trained up to perform these duties or many aspects of my first list above? Nurses interviewed for

the study for example believed that they had care planning expertise and that they treated patients holistically. Clearly, complex practice involving dysfunctional family dynamics, safeguarding and palliative [social] care are prominent areas of specialised endeavour requiring social work training and experience. Unfortunately for the most part due to the sensitivity of this work and study inclusion criteria, the aforementioned areas were not represented in my research findings. Unlike non-complex general hospital discharge planning they could not easily be added on to nursing or occupational therapy for example. Complex needs and situations nevertheless, by their very nature, do not always reveal themselves during a quick assessment on the hospital ward.

Finally, social work is said to be a moral profession (Statham and Kearney, 2007:101) whose value base and adherence to ethics remain crucial topics for debate (Shardlow, 2002:31). Justification of the *professional* role for hospital social work lays in its aim to relate to other professionals equally; clarity about and ownership of responsibilities in connection with vulnerable people; and the regulation of social work by the GSCC as it strives to ensure integrity of the workforce and continuous development of skills and updating of knowledge by its members.

Following on from reflections upon the study I now look at possible areas for future research.

11.6 Areas for future research

As discussed the study outcomes have raised some questions about areas directly related to the research topic and wider. Firstly, to make a general point about hospital social work – it is often overlooked in research and conclusions arising from mainstream area office practice cannot easily be applied or cannot be translated to practice in a hospital setting. The following are some possible issues, drawn from this study's findings that might merit further investigation:

11.6.1 Hidden activities in social care/caring professions/work

The problem of trying to look in depth at work which social work clients and study respondents may not recognise or want to/know how to discuss was explored in the last chapter (10.2.1.). Two possible approaches to circumvent such difficulties in generation of this sort of data could be to design an ethnographic study in which the researcher if an 'outsider' can conduct non-participant observation, perhaps

'shadowing' social workers so that they become used to the presence of another at meetings, interviews with service users and so forth. Ethical concerns would be plentiful and permissions would be required beforehand. Practitioners might still be able to conceal parts of their endeavours that they wished to remain hidden and for that reason an insider already working in social care could adopt participant observation and if prepared to be honest and open within reason could achieve successful practitioner research. To broaden such a study for a comparative strategy social workers and/or carers could also be asked to keep detailed diaries of their day activities over a specific period and these could be used as a basis for one to one interviews.

Descriptive narratives of the less concrete, more nebulous aspect of social work activity could be interesting to analyse. Unpicking 'conversation' through observation of practice and using conversational analysis of recorded narratives or thematically based upon the work of Carter and Everitt (1998) as referred to in the last chapter might be a fruitful approach.

11.6.2 Multiple moves

This may of course be rectified shortly but at the time of writing there was no research found which investigated the effects or even experiences for older people who have multiple moves on discharge from hospital. Certainly in the study hospital there was expectation that older patients would finish some treatment and therapies in rehabilitation units at other sites around the locality. For those who then went into care homes but there was no permanent place available, transitional rooms were 'offered' in anticipation that they should be accepted, rather than occupy an acute bed any longer than was necessary. Some older people indeed may have had to undergo both types of temporary 'housing' after moves within the hospital. The latter was in fact criticised by the NSF review (CSCI, NAO, CHAI, 2006). There has also been work done looking at the harmful effects of care home closures (e.g. Hallowell, Jolley and Morris, 1994) resulting in moves for older residents with dementia. However for those who are able to speak for themselves and communicate more easily an indication of the difficulties of relocating is given by various campaigns around the UK to stop care home closures and legal challenges mounted or supported by older residents (Tanner and Harris, 2008).

Related to this area is that of decision making, moving and factors that come into play when older people move back home from a care home placement, which

happened to two service users from this study. One was actually in a transitional unit but the other was supposedly permanently placed. Social workers who took part in the study reported that for a small number of older people who were in hospital for longer than average stays, their physical health and/or level of functioning did improve in the short-term. However, if older people are left on a ward, particularly without access to therapies, they can become institutionalised and their physical functioning can deteriorate (Swinkels and Mitchell, 2008).

Additionally there are issues for health and social care assessments when older people are in hospital for only a short period of time and may be deemed ready for discharge before their condition has stabilised, another area of interest that deserves closer inquiry.

11.6.3 Inequalities and discharge from hospital

It has been commented upon elsewhere (Glasby, Littlechild and Pryce, 2003) that there has been insufficient research conducted with those sensorially or cognitively impaired or those whose first language is not English to consider how leaving hospital and areas such as decision making and choice might be for them. Lack of confidence and self-esteem were apparent in even the most educated and articulate of service user participants in this study, older women patients especially. The oppressions of ageism, sexism and racism can combine here and social class or poverty are further considerations. The latter tended not to be a major issue for most study participants. However in larger urban areas with all the usual associated inner city problems, older residents especially the frailer and oldest, can be isolated socially and physically. In neighbourhoods where housing generally and facilities are poor, incomes low and unemployment, drug and alcohol addiction comparatively high, discharging frail older people back to less safe communities raises a whole host of difficulties for them, their informal as well as formal carers and professionals involved. Some of these issues are looked at below in the next section.

11.6.4 The role of families

There is quite rightly an emphasis on needs of carers of older people leaving hospital and this study demonstrated how more still has to be done. The role of relatives in decision making has been interesting to consider, how often they act on behalf of older patients ready to be discharged in attending planning meetings,

finding care home places and so forth. Further research could be carried out on making more use of family members as advocates.

It has been pointed out that relatives can be over-protective towards older people steering a more cautious approach than the older person might wish for his/herself (Lymbery, 2005). The families of service user participants nevertheless impressed as being benign and positive in their relationships with the older service users, although there were some minor points of conflict between the two groups noted. However for a minority of older people there is evidence nationally of wide scale financial, psychological and physical abuse of older people that often goes undetected or unchallenged by professionals (Mowlam et al, 2007). Abusive and exploitive relationships can influence decision making on discharge from hospital from relatives/friends with vested interests to maintain the older person at home in order to misuse their finances or conversely to hasten the persons move into a care home where the property is in trust so that it can be sold or used to relatives' benefit.

The role of friends and networks outside of the family was something that did not feature in this study, perhaps not surprisingly as I was not looking for these aspects. I suspect that many of the older service users had ceased being able to be active in the community.

11.6.5 Emotional needs of older people and their carers

As reported above there was little concrete evidence from most of the non-professional study participants that, even if they felt that their emotional needs following discharge required addressing, that the social worker was the person they would have wished to turn to for such support. Nevertheless as also indicated, given that the social workers had little time available to form relationships and to offer emotional support this was not a surprising or conclusive finding. However as discussed in the literature review there have been studies showing older people's anxiety at leaving hospital (e.g. Kvaal and Laatke, 2003) and difficulties in adjusting to life afterwards (Baldock and Ungerson, 1994) confirming this study's findings regarding user and carer participants coping with loss and transition. Those service users who went to live in care homes had to adjust to a new life, which may take a long time (Cook, 2007). Many felt isolated unable to communicate with the majority of fellow residents, which is something that deserves further research attention.

There has also been research demonstrating the important role that social work can play in giving emotional and practical support in palliative care (Beresford, Adshead and Croft, 2006a). Moreover although it did not feature in the NSF for older people (DH, 2001a), the NSF for long term conditions (DH, 2005) does make mention of the crucial part that emotional factors play in coping with chronic illness, but it does not suggest how such needs might be met. This whole neglected area of tackling psycho/social dimensions of health calls for further study: in particular how social work can step in to assist service users, the majority of whom will be senior citizens. If the terminally ill and those with chronic conditions, those with HIV and kidney diseases are allocated a specialist social work service in many hospitals, why do the majority of older patients have to settle for less i.e. care management? At the time of writing the use of talking type non-chemical therapies as a choice for the mentally ill has been recommended by the Department of Health. Furthermore future generations of older people who have not endured world wars may be less stoical and more willing to seek and verbalise a need for emotional support.

11.7 The way ahead for hospital social work

At this point, although the national debate about social work roles and tasks discussed in the last chapter is officially concluded (GSCC, 2008) it seems appropriate to consider some constructive possibilities for hospital social work in the future. Assuming that current levels of expenditure on social care for older people are not going to increase significantly to outstrip the growing demand from a larger population of over 75s, the room for manoeuvre will be tight. So many of the improvements to practice that could make a difference to older people's experience of leaving hospital hinge on the availability of person-power and time. There has nevertheless been some reference to reducing the number of performance targets within the NHS, by former Secretary of State Alan Johnson in 2007 (DH, 2007a) although his successor's views on this are not yet clear. If this trend were to extend to social care, bureaucratic reporting may lessen and free up time for more human contact. However, at the time of writing the future central funding of social care services is uncertain, and the coalition government are planning major public expenditure cuts following the general election of May 2010.

I have not included a discussion of inter-professional working, because this is seen as inextricably linked with the historical separation and financing of health and social care. In other words problems are likely to remain under these structural arrangements, regardless of 'tinkering' at the edges with joint trusts and

multidisciplinary teams, for instance. It would have been interesting to gauge the effect of the single assessment process for example in the study hospital, but it was behind schedule and was not in operation during the period of the research. This is not the place for detailed exploration of policy or practice issues however.

The following are suggestions for practice, based on the research findings:

1. Managers/teams could try to ensure that older people with social care needs are referring themselves/being referred for social work input in hospitals. There was little evidence of publicity or information about social services on the wards of the study hospital, so that patients could make enquiries. It seemed that the hospital team took education of health professionals about the role of social care seriously, but more could be done to inform the public.
2. Information for users and carers needs addressing at all levels i.e:
 - Training for staff on financial procedures including personal coaching and time allowed for reading procedures
 - Clear and plain written information for users and carers to read and keep
 - Recognition of the importance of giving and reiterating *verbal* information to users and carers and referring or signposting welfare benefits. Separate meetings with individuals or families may need to be set up to give time for them to absorb complicated processes such as care home admission procedures.
3. Negotiating expectations for users and carers for length and depth of social work intervention from the start, giving them advance knowledge of social services role post discharge if possible:
 - It is agreed that there is role for hospital social workers in advocating, informing, supporting etc (McLeod and Bywaters, 2003) but how can they reconcile user expectations with constraints of 'the system'/time?
 - Carers of service users particularly valued having a named social worker to contact for any queries or advice post-discharge; it is acknowledged that this is a difficult area as hospital social workers felt under so much pressure to move on and deal with the next hospital patient.

4. Value and publicise parts of social work practice that can work well, and make a unique contribution to multidisciplinary teams: social work support and knowledge of resources for example (e.g. Hopkins, 2007). Participants in workshops looking at social work roles and tasks nationwide also called for this to happen (GSCC, 2007). Taking this further, the question has to be asked whether closer collaboration with health partners that find it so difficult to use a social perspective is in the best interests of service users. Surely working at more effective communication within and between bodies is the key for improved services for older people?
5. Although decision-making re post discharge care is complex, older people are often not fully involved, their family playing pivotal role (SCIE, 2006). So how can social work respond to this challenge? One of biggest dilemmas for social workers here is reconciling the role of carers with the rights of the service user, including the right of that person to delegate decision making to a trusted relative, friend or professional. Both these perspectives are also often at odds with hospital discharge processes as discussed
6. Social work role re globalisation: Mark Lymbery referred to the holistic and anti-racist values and stance of social work (Lymbery, 2006). As the numbers of older people from minority ethnic groups increase coupled with greater migration and mobility within and between nations, social workers will have to respond to changing social care needs and are well placed to do so because of the profession's value base.
7. Finally, an idealistic rather than realistic plea to social workers in general. More spokespersons are needed to speak out for social work and social care, particularly where services are under threat and regarding broader issues such as health inequalities. Situated in a health setting it is particularly difficult for hospital social workers to voice their opinions openly, and this probably explains the dearth of critical comment from them on the passing or enactment of the delayed discharges legislation. In the study hospital the social work team were clear that the latter has had a detrimental effect on both their own practice and the welfare of older patients. Surely this is not the only hospital where social workers and others share these views, but it has been left to academics, some

from outside the profession, to comment (e.g. Askham, 2008; Henwood, 2006; Glasby and Littlechild, 2004).

11.8 Conclusion of the conclusion

The twin objectives of this thesis with relevance to social work and older people have been met. It contains an exploration of older service users' experiences of leaving hospital and an examination of the role of social work in that process. This is one of the first qualitative studies of hospital discharge following reimbursement legislation and as such one of many that will build a picture of the situation facing older people leaving hospital in contemporary England. Within the limits of a single sited, small scale project an investigation into the effects of reimbursement; the third study aim was also completed, even if findings were not conclusive here. The contribution to knowledge is two fold it is suggested, in that two kinds of knowledge have been created: user or carer and practitioner. Service user and carer participants' stories are individually unique: their contribution, their resilience, their comments on how they were treated (for example how they found out what was going to happen to them) can usefully contribute to the knowledge base around older people's discharge from hospital in a changing environment.

The practitioner knowledge can be extended to encompass the experience of multidisciplinary working, of which hospital social work, sited within a health institution, is surely the most *intense* form. In the hospital setting the effects of loss of power as a result of government policy from 1990 (NHS and Community Care Act, Great Britain, 1990. *op.cit*) to 2003 (Great Britain, 2003.*op.cit.*) have been made apparent. Two main themes can be found with regard to practitioner knowledge. Firstly, and possibly unique to this thesis, there were the 'hidden' aspects of the work that I searched for and found fascinating to fathom. Secondly, in the last chapter, the development of the model – building on Karen Postle's work (Postle,2002) - of the social worker facing multiple tensions in their engagement with the service user, can be traced in the thesis, from the search for the 'social' part of the job in the literature, to the 'constraints' found in analysis of the data to a synthesis of competing demands from further exploration of the findings from users, carers and professionals. The model was modified to encompass hospital social work, the interaction with all stakeholders and uniquely how these practitioners were addressing the issues and endeavouring to reconcile those tensions.

Appendix 1 – Personal afterward

From practitioner to researcher, carer and service user, but always a tea drinker

In the introduction to the thesis I wrote about my background as a social worker and care manager. In fact it was a swift transition from one week saying goodbye to service users and team colleagues on the Tuesday to embarking on a full-time research project on the Wednesday morning. The first task was to select a research topic and think about my aims and objectives. Little did I realise that one year later, about to start interviewing service users leaving hospital that my 78year old father would be diagnosed with untreatable cancer. He had several spells in hospital and I found myself as my parents' advocate regarding support for my mother and for post-discharge social care services (which took over two months to arrive due to staff shortages). While attempting to write up and analyse my data I too became my father's part-time 'hands-on' carer in the last 6 months of his life. Following my father's death, I began experiencing some health problems myself and was admitted to hospital for tests becoming thereafter a patient and service user. It was interesting to be on a thoracic/cardiac ward (in my study hospital) sharing a room with 4 or 5 older people, most of them very anxious to leave. I saw both nurses and doctors trying to persuade two of them to stay longer – there did not seem to be any pressure on patients to leave for speedy discharges. Furthermore I now have first hand experience of an OT assessment of my functioning, including those questions about use of the bathroom! But what upset me most was the withdrawal of the early morning cup of tea on the ward and again I thought about the significance of seemingly minor phenomena – the making and drinking of tea and how that had featured as important in my very first job in a care home and later as a qualified social worker when service users would more often than not give me tea on arrival, if they were able. For those unable to mobilise, I would offer to make them a fresh drink, so countless (non emergency) visits over the years started in this way, which was preferable to immediately producing an assessment form and trying to gather those facts as quickly as possible. Doubtless I was considered inefficient and the relevance of all this to hospital social work with the *rarity* of sharing cups of tea maybe tenuous, but I wish to end by summing up the essence of the job, the relationship or the interaction:

'the best care involves the drinking of copious amounts of tea. For tea means talking face to face; talk means humans are interacting, and interaction is appropriate to caring.' (Blaug, 1995: 434)

Appendix 2 – Case examples

The first illustrative case example is in the second part of Chapter 5 (5.4) to give descriptive detail on the level of an individual older service user participant. The methodology and rationale for the construction and selection of case examples are in the introductory section to that case example 5.3.1 and 5.3.2.

Case example 2: Harry (U10) and Lydia (CO6)

Background

Following a visit to another service user participant, the care home's manager had mentioned that Harry (U10) could be an interesting and informative resident to talk to on his experience of coming out of hospital. I followed up this information with the allocated social worker and then wrote to Harry and his wife Lydia (CO6) to arrange an introductory session with them, which they agreed to.

Harry had worked for many years in the army, then for a confectionary company and during his retirement he continued being a very active citizen, living with his wife in their large house in a village on the edge of the study town. In spite of recently suffering a heart attack and then a stroke, Harry was a jovial looking man who was frustrated by his current surroundings and state of health, including lack of mobility, dexterity and dysphasic speech. In our initial meeting he told me about his circumstances and background and he said he was happy to take part in the research with his wife if she was agreeable so I left documentation for them both to consider.

With Harry and Lydia's (CO6) permission a tape-recorded interview of about 45 minutes long took place in Harry's room in a care home. It had a pleasant view of the garden, was slightly bigger than transitional unit rooms I'd seen in the building, and with more photographs and personal effects. Nevertheless, we had to bring in an extra chair for Lydia while I sat on the bed with the tape recorder, making the space feel somewhat cramped. Lydia was probably a little younger than her husband and less forthcoming to begin with. She appeared quite thin and had a tired, drawn facial expression.

The interview started with the couple's opinion of the care and treatment provided in hospital. For Lydia it was "very good" and as the closest relative she had received kindness, sympathy and had been kept informed by doctors and nurses; but Harry had reservations. He believed that he should have had more physiotherapy and found it hard waiting on the ward seeing younger patients receiving this. Lydia pointed out however that for most of the hospital stay her husband was not well or strong enough for physiotherapy in the opinion of the staff involved.

Experience of loss

In January 2004 major changes to the couple's lives began when Harry suffered a heart attack. Triple bypass surgery on his heart was performed and he made a good recovery. Harry was just starting to live a more 'normal' life - gardening and driving again, when he had a massive stroke in that August and so he was admitted as an emergency to the study hospital. He was not discharged until the following January 2005 to a care home where he was living during the period of the study.

In the course of the interview Harry mentioned the loss of his 'lovely car' and therefore another aspect of independence, but did not refer to his home apart from in terms of the cost of maintaining it. The events leading up to the discharge were described as "very upsetting" both because the hospital doctors said they could do no more for Harry and along with the man in the bed opposite who "cried and cried" about this - he would need to be found a place in a care home quickly. Harry further believed that he needed hospital treatment and care and therefore should not have to be discharged. Doctors had firmly stated that it would not be feasible for him to return home, both because of his care needs and his wife's health. One of the senior nurses (?) in particular was sympathetic and agreed that Harry could stay in hospital for another couple of weeks, at least until after Christmas.

Information, choice and decision-making

A meeting was held on the ward with social worker, doctor and nurses, Lydia and her daughter. Lydia told me her daughter was not impressed with her husband's second social worker's attitude at their initial meeting; mainly because of the perceived flippant way she spoke to Lydia about not having to leave the family home. The social worker apparently failed to give clear financial advice regarding pensions, and whether the property was counted for assessment purposes. Paying

fees and associated issues were a major worry for Lydia and Harry. Lydia attended a seminar run centrally by the local authority, contacted Age Concern and SSAFA and then wrote to Citizens Advice. She has tried to get a straight answer on the situation when savings drop below £20.5k, and the council start contributing to the care home fees, i.e. will this mount up as a debt against their house? Harry is also concerned about maintaining their large property and paying the bills. An old family friend who is an accountant has been advising them and they have just sold some shares to help meet care costs.

Lydia was given little information about care homes in general it seems but was handed a list of places to try for a vacancy. Neither of them were apparently given any other preparatory help or advice, although they had experienced a care home environment from visits to an Aunt, resident in another city. Lydia knew she wanted her husband to live in their village so she could visit daily. B care home impressed her as being pleasant and clean - in contrast to the hospital ward, they had found - and so Harry's name was put on the list. It was not long before a permanent room was available but meanwhile the social worker also offered them a 'transitional' bed on the top floor of the care home. Lydia declined this offer on her husband's behalf preferring a pleasanter room and a permanent place for her husband, not wanting him to have any more changes.

Regarding the actual discharge to B care home, it appears that Harry and Lydia did have some control over the timing of the move having found the vacancy.

Adjustment and transition

For Harry it was very difficult to adjust to his new surroundings and he was pretty devastated for the first few days according to his wife. However things have gradually improved helped by feeling physically stronger – he can now move limbs previously incapacitated due to stroke. Harry takes part in activities provided, and enjoyed planting out tomatoes, which are now flourishing on the veranda. Once his electric wheelchair arrives he will be able to go out and about, but he has had to go on a strict diet to be the right weight to use one, which hasn't always been easy! Another big disappointment for Harry is that there are few residents he can have a conversation with, as so many of the others have advancing dementia or communication difficulties. The staff do seem to try to make up for this and he has a good relationship with them admitting that he does occasionally give them a hard

time. Some negative comments were made about non-white and non-UK staff unfortunately. Lydia lives less than a mile from the care home and is able to visit her husband daily.

Relationship with social worker

Lydia's description of her contact with the social worker was an example of the importance the way the discharge process was handled to users and carers, including how professionals spoke to them. I suspect that in the hospital setting where families are on unfamiliar territory and feeling anxious about a loved one's health and future, sensitivities may be heightened. Relationships seemingly started with difficulty in that the first social worker that visited Harry on the ward asked him to sign a financial form, which his wife felt was the wrong step to take as she held 'power of attorney' for his financial affairs. From information given by the second social worker after the planning meeting referred to in Information section above, the couple decided to proceed with arranging the care home move themselves. However they then commented that no one from Social Services visited Harry or enquired whether he was settling in satisfactorily. Lydia did acknowledge that it was possible the social worker had visited her husband on the ward while he was poorly or asleep and maybe was unaware of her/unable to talk to her

Regarding "emotional" support for the pair during this stressful period of their lives - their daughter sounds as if she has been very supportive, but I'm not certain whether she even lives nearby and if she has a young family of her own to look after. Harry's former employers have been helpful and apparently have quite a social network, which Lydia can turn to. SSAFA have been very attentive to her too, but Harry would like to have contact with them. In fact they both felt that Social services had been of no help at all really.

In response to the question: 'What could have been done to improve the quality of Harry's discharge?' Lydia summed up her feelings very succinctly:

" A little bit more talking to you [her husband] and a little bit more help..."

Conclusion to interview

I expressed my appreciation verbally and in writing to Lydia and Harry for giving me so much of their time and their thoughts, very useful as anonymous contributions to my study of hospital discharge. I also asked them if they wanted to add anything

else, so let the final words come from Harry, who did strongly believe that physiotherapy should have been available to him and, in the “absolute injustice” of a system that does not provide free care for those that need it. Lydia asked for a copy of the transcript, which she wanted to receive via post rather than in person, and I did not hear from her afterwards. When I tried to contact her, I heard that Harry had been taken ill again.

Reflections

After a slightly hesitant start mostly on my part, the interview discussion soon started flowing and it became more of an issue not wishing to interrupt the couple’s interaction to re-direct the conversation for the purposes of the study. As with other service user and participants they had much they wanted to air about recent episodes endured in their lives including some heartfelt grievances about the care system. There were a few sub - topics on which the couple disagreed and they amicably agreed to differ.

A dilemma for me as a previous social work practitioner was whether to explain certain actions of the social worker of which there was criticism. For example once Lydia had chosen to find a care home place and set it up herself, the social worker may well have been told to close the case and it would have been more difficult to follow up Harry’s progress in the care home. I did refrain from commenting on this or on the problems with financial information. I did not know in actual fact whether Lydia had tried to contact the social worker to seek advice on this. Furthermore I also became aware during the interview of the dangers of relaxing in the session and losing a sense of one’s role and responsibilities, for example by reverting to an over - casual conversation style and asking closed questions.

Case example 3 – Elaine (C11)

Introduction

Elaine (C11) was unusual in that she unlike the other case example participants had not been a hospital patient herself, but was one of the four talking about their relatives who had dementia. These older people were unable to participate themselves, as they could not give informed consent in the opinion of their social worker; hence they had to be excluded for ethical reasons. I had wanted to locate and relate part of these older service users’ stories however. They were from a

significant and increasing proportion of the population of over 75's with dementia. Their families too I knew had particular issues to face and I wanted to hear what they had to say.

I had to travel some distance from the town to meet with Elaine who lived in a farmhouse at the edge of a village. Following her agreement, the social worker had given me her name and I arranged a visit with Elaine's consent. Over the telephone I explained the nature of the study to her and then sent her some written information to look at meanwhile.

With a lively dog calmed, I was shown into a light and airy conservatory for our discussion. Elaine was in her forties I would estimate and a working mother of two school age children, who were not around. She worked 4 days a week as a child-minder for infants who came to her house. Elaine was very agreeable to the discussion being taped and to sharing her opinions of the services she and her mother received, as described in the following account.

Background

Elaine's mother Mrs Fair, now 87 lived in another town about 20 miles away. Almost six years previously Mrs Fair had developed dementia and her daughter noticed a gradual deterioration in her mental and physical state. Elaine explained how to begin with she had thought Mrs Fair was simply becoming a little absent minded, as they had frequent contact. Elaine began to worry when more than once her mother caught the wrong bus to visit her. Eventually Mrs Fair was assessed by her GP and dementia was diagnosed, whether at that point services were offered it is not known, but for a few years Mrs Fair continued to live alone with support from her daughter who living some distance away was only able to help with some domestic tasks such as shopping and laundry. Finally Mrs Fair became seriously ill with low blood sugar as she either had not wanted to eat and drink or was not remembering to do so. She was admitted to hospital as an emergency where she stayed for about 6 weeks.

"My mother does have a big issue with privacy, she doesn't like other people to know anything at all. She was staying here when she was 1st poorly and my son was helping her to go to the toilet and she was so upset about that, it was taking 2 of us to get there and back. I don't whether she'd had a stroke but over a weekend, she just went totally downhill, she'd had an incident before and went to y hospital and they just turned her round and sent her home so I thought I'm not letting her go there again. When the ambulance

came I said please can she go to x hospital [the study hospital] as she lives in x and it was a totally different experience”

Elaine spoke here in a very matter of fact way about a time that must have been incredibly stressful for all concerned.

Experience of loss

With illnesses such as dementias Elaine has lost some or much of the person she knew as her Mother, in addition to a lost or changed relationship:

“When she comes here she thinks we’re going to keep her and all she can think about is going home, and so she has to have constant reassurance that its still there.”

Nevertheless Elaine was very matter of fact about what had happened to them all, especially to her working virtually full time with children to support in addition to her Mother. She gave the impression of a gradual deterioration in Mrs Fair’s health, punctuated with dawning realisations of lost and irretrievable faculties with the passing of time. Mrs Fair had literally lost her short-term memory. Like others with dementia she may have retained her connection with the past and knowledge of distant years gone by. Elaine described how she witnessed the effects of dementia on her Mother and what it meant for her, often 24 hours per day:

SF:“It must have been very hard for you visiting her and being a long way away?

C11: It has especially when she rings up and panics and by the time she’s got thro to you, she doesn’t know what the matter is she just knows she’s upset and sometimes its 3 00 in the morning and you’ve got to turn out, but luckily this person I work with is very good, she comes in and I do whatever it takes”

Fortunately for Mrs Fair, the loss of her own home on hospital admission and then transitional care admission, was short lived and to the best of my knowledge she could recall her own home.

As with some of the other service user and carer participants, Elaine recognised how she had gained from her Mother’s admission to hospital and ensuing referral for support services. This had led to Mrs Fair trying nursing home care – not a success but home care input which followed that experiment was worked well, from her daughter’s perspective:

“Wonderful, when I think how I’ve struggled with her all these years with absolutely no help at all and now we’ve got 3 carers and between them they do all 4 visits. And I’ve bought a big diary and we all write in it, so it keeps the communication open and then if they’re slightly worried about something they ring me up. They’re just brilliant.”

Information, choice and decision-making

Elaine was positive about her Mother’s stay in hospital: “she was treated as an individual which I liked, she wasn’t just a number”.

Staff on the ward were helpful in giving information to Elaine regarding what she could bring in for her Mother but gleaning information on the progress of Mrs Fair’s illness and seeing a doctor about this were ‘virtually impossible’. Elaine explained that working virtually full time it was not easy for her to arrange to see a doctor during the day, neither was it easy for her to sort out Mrs Fair’s complex finances. She commented that having to talk to or visit *different* departments about various benefits and bills was complex and hard enough for her but would be much more so for a person such as Mrs Fair with less mobility and sensory/cognitive impairments.

From the start Elaine found the social worker was available for advice and information and it was he who initially spoke to her on the telephone. An arrangement was then made for Elaine to meet him individually on the ward to discuss the discharge plans. They had a discussion between them and a decision was reached that Mrs Fair would try respite in the form of transitional care at a general nursing home. I had the impression that Mrs Fair had not been involved in these exchanges, because of the view by her daughter and professionals that making decisions would not be possible for Mrs Fair to take part in, due to the dementia.

Transitional care was just that for Mrs Fair; as after a few weeks at the nursing home she eventually returned to her own home, Elaine spoke briefly about the change of plan:

“Once I decided that it wasn’t the right thing for my Mum they supported me 100% down the other route even though that’s not what they would have chosen. I didn’t have a battle.”

Elaine commented that choice of transitional care was too limited in this locality and did not cater for dementia sufferers needs adequately. Nevertheless in describing the alteration to the plan from nursing care to care at home Elaine seemed surprised that she did not meet with resistance from any staff. [Had the social worker advocated and prepared the 'ground' I wondered?] She nevertheless commented that the assessment performed by a member of care home staff who came to visit her Mother on the ward was too superficial, in that they had not fully absorbed the level of Mrs Fair's dementia and asserted that they could meet her needs, when they actually could not in her opinion.

"She (Mrs Fair) feels like she should put on a brave face and for that age group as well. My Mum was born in 1918 and feels authority is something to be concerned about."

Following further debate with the hospital social worker when it was clear that Mrs Fair was not happy and was unlikely to 'adjust' to the care home, a multidisciplinary meeting was then held in the form of a home visit. Elaine, the social worker and therapists attended to ensure right equipment and levels of home care could be brought in for Mrs Fair:

"Whether she could make a drink and the OT was fantastic she knew that the bed had to be a certain height and the chair and we discussed the fact that she had gas heating and a gas cooker and we discussed how we were going to put the gas cooker out of action so it wasn't going to be a problem and moving her on to microwave meals and this sort of thing which all fell into place really with the planning that they are used to doing – they've seen the pitfalls."

Here Elaine has given a full picture of how a planning home visit worked and how with risk assessments painstakingly conducted, she was able to view her Mother's homecoming confidently. She also described how the decision for Mrs Fair to move out of the care home was made by her acting on her Mother's behalf, having learned of her unhappiness in that institution.

"So I've decided that you have to go for the quality of life that she wants and at least she has got quality of life. Even if she isn't quite as safe as in the nursing home where she was totally upset and disorientated and miserable and she might have lived for a lot longer but you've got to balance it .."

The role of the social worker in this was not clear. Had he visited Mrs Fair or contacted the care home or Elaine to discover how she was doing there? It is likely

that he did telephone to check, but for someone like Mrs Fair often unable to express dissatisfaction verbally he would have been reliant upon staff or relatives to give an indication of her progress in transitional care.

Transition/adjustment

Returning to the earlier period at the time of her hospital admission I referred in the introductory section how Mrs Fair had initially come to live with her daughter's family, then went to one hospital and was not admitted, prior to going into the second hospital. In other words Mrs Fair had undergone five moves to different locations before she finally returned back to her own home.

When it came to the discharge from the study hospital, Elaine felt that it all went smoothly 'a painless handover' with her Mother going to transitional care by ambulance. She did not have to wait long for a place either:

"No once they've decided her time was up and apparently you have to pay a surcharge for somebody per day to the NHS trust? So I presume they keep these places available in the nursing home for when they have an overflow and they need to put people in, so yes it didn't take long at all once it was decided that she was going, they moved her quite easily"

So Elaine did indicate awareness of the delayed discharges legislation and she did not appear perturbed by it. Moreover she pointed out that Mrs Fair found being in hospital difficult, like anywhere else other than the familiar:

"It was just that her state of mind was such that she didn't want to be anywhere except home,"

Transitional care in the nursing home was an unhappy time for Mrs Fair and her family. It was apparently a 'frightening experience' for her, as Mrs Fair could not cope with the other residents around. She retreated to her room and became very isolated. As reported above, Elaine talked too about balancing of risk in this situation and that it became clear that not only could her Mother fall and be alone for a while in her own room in transitional care, but also that her quality of life was more important:

"I thought were they right and I was wrong – stupid idea! But its settled down now and its really worked well and even if we get 6 months or a year, its been worth it and then she has to go into care – the carers think that she's better at home and they see a lot of people."

Making the second move to return home went remarkably smoothly again and Elaine found that it continued to work well with home care support and alarm call back up. Home care staff of which there were a stable group of three managing four calls per day to Mrs Fair were 'just brilliant' and Elaine gave examples of their willingness to notify her if any problems:

"In fact they were worried about her when they put her to bed the other eve but they said they didn't think I needed to come through. Then the next morning I was just about to set off at 6 45 and one of them rang me and said she's fine this morning, no need to come out and that was so kind above and beyond what they're expected to do, they're amazing and she's got used to three of them. If there were more of them she'd be confused, they're tight knit, they all have meetings and they know what's going on. They're from a private agency."

Elaine summed up the difficulties faced by those with memory loss and their families in adjusting to different home environments:

"She quickly forgets things and once she was in the nursing home she thought that was permanent and soon forgot all about hospital but the one thing she could remember was being at home and that's the problem coming here."

Elaine was referring to the situation faced by many relatives of dementia sufferers who are uneasy out of their home environment, which often seems to worsen with the progression of these illnesses and changes of location. For Elaine this meant she always has to travel to see her Mother and if she does bring her back to their house, Mrs Fair is continually anxious to return home.

Relationship with the social worker

Elaine explained that it was the hospital social worker that had approached her initially to discuss Mrs Fair's future post discharge and from that point he was available for advice and information even after her Mother had left the hospital. In fact she expressed surprise almost at the level of support she had received throughout the process. I did not ask her if she knew how much contact the social worker had with Mrs Fair, but she gave an indication of there being an issue for her Mother when she was transferred to a younger female worker in the community who had conducted the care plan review. Elaine was of the opinion that Mrs Fair related better to men. Moreover the review had not apparently achieved all she had hoped for in terms of amending her Mother's care plan. Elaine had wanted a small increase of care worker time to stay with her Mother while she ate and to do some

cleaning, both seen as important tasks by her especially as Mrs Fair was had a poor appetite. Apparently the reviewer had insisted on the latter being present and Mrs Fair had then declined an increase in service, but as Elaine pointed out her Mother has little awareness of her own needs or recall of anyone coming to her home at all due to the dementia. A further review after six months was arranged but meanwhile Elaine remained concerned for her Mother's welfare. She could contact social services if she was particularly worried but added that the next review had already been scheduled earlier – six instead of twelve months.

Reflections on interview

This was probably one of the most successful interviews regarding flow and pace – from my viewpoint it felt more like a relaxed conversation, partly because we seemed to 'naturally' cover most of the important areas vis a vis the research. Elaine was prepared to be open about her views on many areas of interest and relevance. For example she gave helpful insight of a daughter's witness of a parent with dementia's decline in functioning, what that meant to her and her family and the relief felt in receiving support services and having understanding staff to talk to from OT and social worker through to home care. It may have helped that she was closer to my age than the majority of carer participants and we shared certain characteristics such as being a working parent. Furthermore it is important to remember that not being asked about her own or even a partner's experiences gave perhaps greater distance from the subject, making it easier to talk about? That is not to deny or minimise the difficulties the family went through with Mrs Fair's illness, followed by move to a care home and then eventual rehabilitation back in the community. Elaine as a childminder was also familiar with local authority administration and she had a certain amount of knowledge on older peoples issues over and above that gained via acting on behalf of her Mother, such as on the delayed discharge debate.

The only negative comment I would make on our discussion was that I sensed Elaine would have had more to say, as lack of time for her probably prevented her elaborating on points made any further. I found myself wondering how far I should also have probed further given the time constraints – and I maybe erred on the side of caution in not wishing to detain her for too long?

Mrs Fair's unhappiness in transitional care but having her daughter to advocate on behalf for her to move out made me think about the plight of all those other residents in a similar position. It is therefore quite possible that those without relatives who cannot communicate may be left to languish in inappropriate environments. Of course luckily for Mrs Fair she was able to function at home alone with domiciliary care. This was yet another issue of importance however – I wondered how long Elaine would have been able to support her Mother alone i.e. had it not been for the changes brought about by her hospital admission.

Case example 4 – Gertie (U09)

Introduction

The following case example draws upon an interview transcript and field notes of an introductory meeting, reflections on both sessions and of a brief outline given by the social worker who referred Gertie to the research study. Unfortunately because the only relatives or informal carers involved had already returned to their homes some distance away, it was not possible to talk to them to gain additional perspectives on Gertie's hospital discharge and move to residential care.

As detailed in Chapter 6, this participant was selected for a case example exploration as one of many service users who had moved to a care home from hospital, but had made a positive choice to do so. However as will be shown Gertie still experienced 'loss' in another sense and she was also able to discuss the contribution made by two social workers but in very different ways in each instance. Her descriptions illustrate the problem both for the study and for feedback on hospital social work in general as can be seen below.

Background

Gertie had been described to me as a 'sweetie' by the residential care homeowner who took me to meet her following referral to the study by her allocated hospital social worker. This was an initial introductory meeting to explain the research study and what participating involved and to give inform sheets and consent forms for her perusal.

For both interactions, I was taken up to Gertie's room which was in fact a bed-sitting room – comfortable chintz arm chairs with lace antimacassars, plenty of framed photos, potted plants and a mullioned bay window looking out onto the trees,

flowers and grass of the home's garden. I mention this detail to convey the image of a homely environment and setting for the discussion, and one on which Gertie had clearly made an individual mark in a short space of time. In one of the chairs sat Gertie, a small thin slightly bent woman, smartly dressed with newly 'set' hair. She got up to greet me, smiling, holding her walking stick. At that first meeting Gertie was extraordinarily open and friendly. She had quite strong opinions on many of the issues we discussed and seemed to enjoy talking about her experiences and consequently the conversation flowed easily. This contact was almost as long as the actual interview itself and from my perspective a helpful rapport was established between us.

Gertie had a strong Scottish accent; I could not narrow it down further, so I wondered what had brought her to England? Furthermore there were pictures of her with a man taken perhaps a few years previously looking happy together standing next to flower beds in a much larger garden than the one down below. There were other photographs including one of a man with a different appearance in an army uniform and clearly from World War 11. What had happened to him and the children I also saw captured on film? Gertie went on to explain all including the circumstance of her arrival at this care home in the following account. She agreed to a second visit to talk about her experiences of hospital discharge, to taping the interview and to using the contents for the research study afterwards.

Turning the clock back 90 years finds Gertrude born into a poor Scots household. With little employment available in her small hometown Gertie left it and her family at the age of 22 for England and specifically the northern town where the study is based. She found work at a confectionary factory and soon met her husband to be, a fellow employee. All was well for nearly four decades for the couple who raised two children, and survived the war years. Gertie was promoted to a position she described as teacher within the factory in spite of having left school in her early teens due to 'poor health'. Then in his sixties sadly her husband fell ill and died. Some years later however Gertie met up with an old family friend and she re-married. She explained that she was fortunate in finding happiness with both her partners with whom she also enjoyed ballroom dancing in particular. Her holiday snaps were produced and I was shown these and the records of other joyous occasions. Gertie continued working as long as she could and was a supported housing warden until her retirement. She remains close in spirit to both her son in

daughter who live a long distance away, but who were able to visit and support her in hospital, when she was taken ill.

The experience of loss

After caring for her husband for some time, culminating in his admission to hospital, Gertie suffered a heart attack, and this episode ended in further tragedy for her. Although she spoke in a matter of fact manner she did refer to 'the stress of it' but did not wish to give much detail of either hospital admission - unlike many other user participants - or the preceding months which must have been very hard for her as a carer with little support. Moreover as far as it is possible to tell from our conversation, Gertie was one of those service users who had lived an active life that was suddenly interrupted and irrevocably changed by her own and her partner's acute episodes of ill health. The period of hospital treatment, which followed, was about six-eight weeks for Gertie. Unfortunately after she returned home her husband died in hospital. She was then re-admitted because she had fallen in her garden and gashed her leg, whilst her husband's body was apparently still in the mortuary. She was keen to show me where her leg was bandaged but the wounds were 'healing nicely'.

Unlike other service user participants Gertie seemed not so keen to recount the detail of her hospital stay, save that she had no complaints and that they were '*all wonderful*'. She did impress as someone who thrived in social situations, as she seemed to be doing in the care home. In that sense she possibly would have coped relatively well with a hospital admission and as she commented there were no close relatives or friends nearby to miss.

In the thematic chapter on 'Loss' Gertie features as one of those who had benefited via the hospital discharge process from access to services, in her case to a care home place. Had she tried to apply for the latter from the community assuming she had she known who to contact, undoubtedly there would have been a longer wait both for assessment and funding. The eligibility criteria under Fair Access to Care may have been more tightly administered too, depending on her level of functioning at home.

Decision-making and choice

Following the death of her husband and her second hospital admission, Gertie made up her mind that she was not going to return to her own home to live alone, mostly for social reasons:

“ First reason was my husband wasn’t there and second reason I had no friendly neighbours and 3rd reason I knew I couldn’t look after myself and I realised that now was the time to go somewhere because I had been thinking about it for sometime”. **U09**

I was so engrossed in our exchange I omitted to ask her opinions on obtaining information from staff either about the progress of her own illness or that needed to make informed choices on her future, the process of arranging a care home move, for example. I also wondered whether either social worker had conveyed the availability of a care package to provide support in the home. She did not raise these matters herself and she mentioned no particular problems in these respects.

Gertie explained that her son and daughter had made it clear that it was her decision to move to a care home which they would support as she described in their response to her situation:

“ There again Mum, I don’t care if you wanted to go to Mount Everest, if it was going to make you happy.”

On recounting the professionals’ views of her decision Gertie was less complimentary. She had produced a letter ‘recommending’ this course of action from her GP but even so the Consultant at the hospital and the social worker suggested instituting a care package to enable her to stay in her own home. Gertie strongly believed that it was her ‘right’ at the age of 90 to be considered for a care home place. She seemed upset by what she saw as conflict about this matter in which ‘backing’ came from her family and referred to an interview with the social worker and the doctor about future plans, denying that an actual meeting had taken place with professionals and her family on the ward. The impression given was that she saw the opportunity for greater independence on her terms *within* a care home where she could have her own room and as much help and socialising as she desired or not, within that setting. The allocated hospital social worker was in no doubt that Gertie could have remained at home but also indicated that she was supportive of her decision and the holding of the hospital bed whilst she went on a trial visit was an important step that the social worker apparently argued for.

Choosing a suitable care home was in the hands of Gertie's daughter as she was a 'bright and sensitive' person who would know what she liked. Gertie emphasised that she had delegated this aspect of decision making to her daughter in whom she had full confidence. Once the current room had been found and a successful trial visit set up, Gertie commented that she wanted to look no further as she would become 'too mixed up'. Her bed was held in hospital for her to make a final decision and when she returned to the ward she had the opportunity to consider her future:

" Oh yes, they talked to me and didn't push me at all and said what did I think?"

Adjustment and transition

The actual discharge from hospital was straightforward, not rushed with the timetable seemingly decided by Gertie in conjunction with the care home manager:

SF: "So did you have plenty of notice of when you were going to leave hospital?"

U09: Oh yes, it got to the stage when they said, "We won't send your Mother out until she's got what she wants"

Adjustment to life in a care home for the first time appeared to have been relatively smooth for Gertie who talked more about reasons for not going back home rather than residential care as a positive choice: "no regrets because when I was at home I suffered with a stress condition". Although there was a brief aside in which she was critical of some of the other residents and the potential for socialising with them, Gertie expressed satisfaction with her new surroundings. During both our conversations she had a positive, relaxed demeanour when I asked her view of them and whether the care home lived up to expectations: "It was a relief. X the manager was so good with me and I'm a pretty good judge of character." She also talked about going out shopping with care home staff to buy clothes. Gertie was enthusiastic about her room, the food and the general care home environment, particularly being able to sit out in the garden.

Relationships with social workers

Gertie initially had contact with social services in the intervening period between her first and second hospital admission. Attendance at a lunch club had been arranged then and even a possible move to residential care either permanently or for respite,

but was discounted by her at that point for the time being. Gertie beamed enthusiastically while speaking about her former social worker:

SF: "Can you say again your opinion of the social work help you had?

U09: Oh wonderful, wonderful, she helped me no end with my nerves, she was a lovely woman. When I went to X lunch club She even took me in her car and stayed with me to help me settle in...

It is interesting to note that to Gertie the term 'social worker' meant the community social worker who she had presumably not seen for some weeks. This seemed to be in contrast to views of the hospital care manager who had met Gertie on the ward and who had visited her at the care home recently. When I asked Gertie directly about her overall opinion of hospital social work intervention she responded fairly abruptly that she had seen nothing further of that social worker since the early conversation with the consultant about her future. This second social worker (hospital care manager) had conducted a review about a fortnight previously which was only discussed briefly: "Someone asked me questions and same as I've told you I said everything was fine" The reference here by Gertie to 'someone' could perhaps be explained by memory loss, which may also account for her acknowledgement of a single visit by the social worker on the ward only.

Conclusion

Gertie's situation has been reported as an individual case example partly because it is an exemplar of a positive outcome and practice, even though it may not have been as such by the participant. It would have been useful to hear more about the hospital social worker's view of her relationship with Gertie – she had spoken about her contact warmly but respectfully - and of her input to the care planning for discharge, although it would clearly have been crucial to maintain confidentiality about interview content. Unfortunately by the time I had returned to the office after this session, the social worker had left the department altogether.

On reflecting about the conduct of the interview, flow was not a problem, as Gertie seemed at ease and keen to talk. In fact that was perhaps more of an issue – how far to direct the focus and how far to let the participant speak on matters of importance to her. Perhaps balance is the key, I did not feel too guilty about covering the subjects of relevance to the study as long as the participant was happy to respond and given plenty of opportunity to raise issues of his/her own. In this situation as with many of the other interviews, the informal conversations during an

introductory visit and before and after the taped part were seen as 'participant's time' but also helped to establish rapport.

The interview ended as Gertie spoke again about her fear of living alone, something she had returned to a few times, but nevertheless on a positive note saying she had found the conversation 'very interesting'. Happily she did not appear to be tired or upset by the experience and we carried on talking for some time after the microphone was turned off but on lighter themes about her family, interests and fashion. A copy of the transcript or a summary was offered, but declined. As with other service user participants I would like to have returned to talk to her to see if her positive attitude to residential care had altered at all and whether I had caught her during a 'honeymoon' period. To the best of my knowledge she was only one of two service users who actually sought a move to a care home from hospital rather than a return to former life, which would have been a different life for Gertie, alone after her partner's death. In one respect Gertie was fortunate – she only required local authority funding of her placement until her house was sold. Others in her position but without property or considerable savings may have been refused full funding on the grounds of ineligibility. At the end of fieldwork in 2006 Gertie was still in situ and I do hope that her contentment had continued.

Appendix 3 - Research project milestones

This table covers the period from the start of the research project to the end of data generation

Action	Background events	Date
Discussion with social work colleagues re research topic		September 2003
Start as f/t PhD student		October 2003
Discuss project with social work manager		November 2003
Approval from senior manager soc services	Hospital Social services reorganise Start of reimbursement	Jan 2004
IPA approved by university		February 2004
Discussions with hospital discharge manager, Age Concern, Carers Centre		February-March 2004
Approval university ethics	Full social services reorganisation from specialist teams to intake/adults/long term	April 2004
Permission and sponsorship hospital consultants/budget holders		April – June 2004
Contract NHS trust		June 2004
Initial LREC approval		June 2004
1 st meeting hospital social work team to request names of participants		July 2004
2 nd meeting hospital s/ws		September 2004
Start weekly visits s/w office	Introduction of new assessment documentation in line with SAP	October 2004
1 st participants potential name received & interview completed	Realisation that older people not on wards long enough to be interviewed	November 2004
Full LREC approval		December 2004
study amendment to university and LREC approved		August 2005
Finished data collection		September 2006

Appendix 4 - Patients' semi-structured interview schedule

Introduction/experience of hospital

- Firstly, how long have you been in hospital? How has it been for you?
- If you know, can you tell me where you will be going when you leave?
- When do you expect to go?
- Supp.Q. Could you tell me at what stage you started thinking about coming out of hospital?(*prompt: on admission > not at all*)
- (Supp.Q. If appropriate: What has it felt like for you to wait on the ward to be discharged?)

Discharge process

- I'm sure you will have had a talk with staff/someone outside friends/family about the plans for you coming out of hospital. Do you know who these people were?
(*Prompt: nurse/o.t./physio/social worker*)
- a) If uncertain/deny s/w involvement)
- What sorts of things did you talk to them about?
 - How did you feel about these discussions?

OR

- b) If remember social work involvement
- What did you think about the help you received from social worker?
(*Prompt: relationship, planning services, help re adjusting to coping with new situation?*)
 - I'm also interested to know your opinion on the way decisions were made about your future, if you feel able to say something about that?
(*Prompt : enough time, information, consultation – i.e. were you able to express your views and preferences? Did you feel you were listened to? Did you feel you had any influence on what has been arranged for when you come out of hospital?*)

Conclusion

- You don't have to answer this of course but is there anything about the planning for you to leave hospital that you would have like to have been done differently?
- I was also wondering how you are feeling about leaving this ward and going to ..?

And finally

- Is there anything else you would like to add to what you have said in our discussion so far?
- Is there anything you've said that you would like to change?
- Anything you want taken out/deleted?
- Can I also ask your permission in using the contents on tape of this interview for my research project? Await response.

Thank you very much for agreeing to answer my questions and for your contribution to the study,

Appendix 5 - Carers semi-structured interview schedule

Introduction/experience of hospital

- Firstly, how has it been for you, with ...(hereafter referred to as: X) being in hospital?
- How do you think X has found it? (Prompt: especially if they've had to wait for services etc.)
- If you know, can you tell me where X will be going when they leave?
- When do you expect X to go?

Discharge process

- Could you tell me at what stage you started thinking about planning for X coming out of hospital? (Prompt: on admission > not at all)
- I'm sure you will have had a talk with staff/someone outside friends/family about the plans for X coming out of hospital. Do you know who these people were? (**Prompt:** D./nurse/o.t./physio/social worker)

a) If uncertain/deny s/w involvement)

- What sorts of things did you talk to them about?
- How did you feel about these discussions?

OR

b) If remember social work involvement

- What did you think about the help a. received from social worker? (**Prompt:** relationship, planning services, and help re adjusting to coping with new situation?)
- I'm also interested to know your opinion on the way decisions were made about X's future, if you feel able to say something about that? (**Prompt:** enough time, information, consultation – i.e. was X able to express their views and preferences? Did you feel X was listened to? Did you feel X had any influence on what has been arranged for coming out of hospital?)
- What about the way you were treated as a carer? (**Prompt:** as last question above)

Conclusion

- You don't have to answer this of course but is there anything about the planning for X to leave hospital that you would have like to have been done differently?
- I was also wondering how you are feeling about X leaving this ward and going to ...?

And finally

- Is there anything else you would like to add to what you have said in our discussion so far?
- Is there anything that you have said to me that you would like to change?
- Anything you want deleted?
- Can I also ask your permission in using the contents on tape, of this interview for my research project? Await response

Thank you very much for agreeing to answer my questions and for your contribution to the study.

Appendix 6 - Staff interview agenda for consultation with participants

Joint working

- Relationships between professional groups working with older people in the hospital
- Relationships between above groups and primary care
- Views on how individual professional contributions are valued in multidisciplinary teamwork with older inpatients.

The discharge process for older people.

- Effects upon older people who wait to be discharged hospital.
- The extent to which older patients are consulted in discharge planning.
- The extent to which informal carers are consulted about discharge plans for the older person they look after.
- Views on the consequences of the 'delayed discharge' legislation upon older patients.
- Views of the impact of the above legislation upon hospital / social work staff
- What could be improved for older people leaving hospital?

Health and social care

- Do participants in this group believe that older people see health and social care services separately?
- Opinions on what individual professions have to offer to the discharge process.

Any other issues of importance to the group not covered in the above?

Approved by X NHS Local Research Ethics Committee July 2004

Sue Fowler

Postgrad research student, School of Health, Education & Community Studies
Northumbria University

GROUND RULES FOR DISCUSSION GROUP

- No right or wrong answers
- All contributions are equal & to be respected
- Whatever is said must be kept anonymous
- Agreement on issues not required,
- & Its ok if there is a consensus too
- Each person free not to respond to any matter
- Moderator has to be impartial!
- For the mike & transcriber one person to speak at a time ideally!



Research Project: YOUR EXPERIENCES OF LEAVING HOSPITAL

Q.What am I being asked to do?

Would you be able to give a little of your time talking to a researcher; to help us find out what it is like for someone like you, or the person you care for, to come out of hospital? At a time and place to suit you, you will be asked if you agree to answer a few questions about your experiences, for up to about 45 minutes.

Q. By who?

Research student Sue Fowler will be conducting the interviews. She has been a social worker for 30 years and is now studying for a PhD at Northumbria University. She has an honorary contract with X Hospitals Trust who with the Research Ethics Committee and X Council have approved the project.



Q. What if I change my mind?

Taking part has to be entirely your decision, and this will be checked at every stage, to make sure you are comfortable about everything. You are free not to

**answer any question you don't like AND to withdraw
any time without giving a reason**

Q. Will my response be kept anonymous?

**Yes - your name, address and personal details will not
be linked to the discussion recording, which will be
carefully stored and destroyed when the study is
finished.**

Q. What is it for?

**It is hoped that a report from the study will eventually
be published, in various formats, so that health and
social care workers and the policymakers can learn from
the views of older people, carers & key stakeholders.**

FOR COMMENTS, QUESTIONS OR COMPLAINTS

Research Investigator

Name: Sue Fowler

[Postgraduate research student]

Sponsor: School of Health, Education and Community
Studies,
Northumbria University,
H214, Coach Lane Campus East,
Newcastle upon Tyne,

NE7 7XA

Contact telephone no:

Email: suefowler@onetel.com

Supervisor

Name: Professor David Stanley

Address: Northumbria University
As above.

Contact telephone no: 0191 215 6261

Email: david.stanley@unn.ac.uk

Appendix 8 – Documentation for social workers giving assent on behalf of service users

School of Health, Education and Community Studies,
Northumbria University,
H214, Coach Lane Campus East,
Newcastle upon Tyne,
NE7 7XA

Tel:

Email: suefowler@onetel.com

Dear ..

Re: Research Study: The role of social work in hospital discharge of older people

....., who is a service user known to you, has a close relative/carer who is being considered for inclusion on a voluntary basis in the above study. Given that this service user is deemed as likely to have difficulties in giving informed consent and in giving permission also for their relative/carer to take part - following research ethics policy and best practice - I would be grateful if you would give your opinion as to whether it is appropriate for their relative/carer..... to be approached.

Information about the research and what participation would entail for Is attached.

Once you have read this information please could you complete the enclosed form indicating your opinion about inviting..... participation and return it to me, in the enclosed SAE.

If you feel you need further information about the research, or if you would like to see the information sheets for carers/relatives please contact me,

Thanking you in anticipation of your help.

Yours sincerely

Sue Fowler
Postgraduate research student

INFORMATION SHEET/CONSENT FORM FOR STAFF GIVING ASSENT

Study title: The role of social work in hospital discharge of older people

Purpose of the study

This small-scale qualitative research project seeks to find out the views of older people and their carers/close relative on: the process of discharge from hospital, how care was arranged and their opinion of quality of services and outcomes.

Inclusion criteria

Patients over 65 years old, and their close relative/carer who have had contact with a social care manager or social worker regarding discharge from X Hospital, who are able to give informed consent to participate, who are not terminally ill or have severe communication difficulties and whose mental or physical condition would not be harmed by taking part.

Do relatives or carers have to take part?

Taking part in the research is entirely voluntary and consent will be re -confirmed at every stage, so that participants can withdraw at any time without giving a reason. Participants are asked to read an information sheet and complete a consent form if they wish to be included in the study

What will happen to participants?

Participants are asked to respond to one tape-recorded interview with the researcher that will take around 45 minutes, held in private and the place and time can be arranged at the participant's convenience. The interviews are semi-structured and informants will be asked about their experiences as a carer or close relative of an older person who has been discharged from hospital, but will also be given the chance to talk about any other matters as they wish. These interviews will take place from Autumn 2005.

What are the possible disadvantages and risks of taking part?

Answering the questions may be tiring, although at any stage the interview can be halted. There is the possibility that the interviews would bring up sensitive issues that the participant may wish to discuss further, in which case time can be set-aside for this.

What are the possible benefits of taking part?

The information we get from this study is designed to help us to understand the difficulties and issues that older people and their carers have after a period in hospital. It will be very useful for those who plan and provide services to know what it is like from the relative/carer's viewpoint. Participants may even find it helpful to express opinions to an outsider who will ensure that they will be kept confidential. Unfortunately there are no financial payments for taking part.

What if something goes wrong?

If participants are unhappy about any part of the interview, they can contact Sue Fowler or supervisor David Stanley, who we will do their best to redress the situation.

There are no special compensation arrangements, should participants feel adversely affected, but if they wish to complain, or have any concerns about any aspect of the way they have been treated during the course of this study, the normal National Health Service complaints mechanisms will be available.

Will my taking part in this study be kept confidential?

All information, which is collected, about participants during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed once analysed and names or addresses will not be attached to tapes or any other records.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at the Northumbria University. Subsequent publication will be subject to procedures in the appropriate journal. Participants will not be identified in any report/publication.

Who is organising and funding the research?

Sue Fowler is a qualified social worker who has practised for 25 years, has a social science honours degree, an M.A., and is currently a full time PhD student under a studentship scheme at the Northumbria University, Newcastle upon Tyne. She is conducting this research as part of a PhD.

Who has reviewed the study?

School of Health, Education and Community Studies, Northumbria University.
NHS Local Research Ethics Committees.
X Hospitals NHS Trust – Research & Development Department.

Contact for Further Information

Ms. Sue Fowler,
Postgraduate Research Student (Full time Ph. D Programme)
School of Health, Community and Education Studies
Coach Lane Campus East,
Northumbria University
Newcastle upon Tyne
NE7 7XA.
Tel:

Or

Professor David Stanley,
School of Health, Community and Education Studies,
Northumbria University, as above.
Tel.: 0191 215 6261

ASSENT FORM

Title of Project: The role of social work in the hospital discharge of older people

Name of Researcher: Sue Fowler

1. I confirm that I have read and understand the information sheet dated for the above study and have had the opportunity to ask questions.
2. I recommend that this service user's close relative/carer can be approached to participate in the research having judged that:
 - Participation is not against the interests of the individual and
 - That the individual's carer/close relative may gain some benefit from participation. Such benefits could include participating in a collaborative environment and having the opportunity to express their views to an independent researcher.
3. I know that participation of this close relative/carer is voluntary and that this person may decide not to participate or may decide to participate but can withdraw at any time
4. If for any reason I consider the service users or carer/close relatives' circumstances to have changed and that participation may now be detrimental to them in some way, I will inform the Researcher and participation will be terminated.

Name _____

Designation _____

Relationship to service user _____

Signature _____ Date _____

1 copy for participant; 1 copy for researcher

Appendix 9 – Comparison of issues in interview and focus group data

Social workers

Arranging care →

Follow-up, contested area→

Reviews→

Time and lack of it generally→

Rushed discharges→

Quality of social work relationship→

Financial information→

Assessment

Administration

Paper and computer work

Coping with risk

Interagency relationships→

Lack of choice of care→

User and Carer Participants

Co-ordination of care package

←Lack of time with s/w

e.g. kindness, empathy etc

Social worker availability

Information provision generally

Adjusting to life post discharge

Carer anxious re patient risk

Advocacy

Patient involvement in discharge

Carer involvement in discharge

Professionals breaking 'bad' news

N.B. → denotes when issue was found in both sets of data. Where no arrow, it only occurs in either set.

Appendix 10 - Categories and sub-themes

The following is the complete set of common categories assigned to the study data from interviews with **service user and carer participants**:

1. Prior to admission

Repeat hospital admissions

Previously independent

Gradual deterioration in condition/sudden onset illness

Services prior to admission

Bereavement

2. Hospital care

View of experience overall

Provision of medical info to users and carers

How treated as a relative

Communication with staff, including 'lack of personal touch'

Cleanliness

Laundry

Recovery?

3. Planning and decision-making

No memory of discharge planning

How assessment re future care options conveyed

How listened to/involved

Consultation

Role of nursing and medical staff

Role of family in decision-making

Choice of care package or care home

Opinion on Choice of care home

Previous knowledge of care home life

Visit to care homes by patient/family

Info given on services

Attendance/opinion of hospital multidisciplinary planning meeting

4. Discharge process

Time of first thought about leaving hospital – e.g. illness affecting early planning

Who spoke to re discharge?

Feelings about leaving

Being told to leave

Waiting for services

Other delays

Feelings about post discharge location

Notice given of discharge date

Trial home visit

Satisfaction with actual discharge

5. Social work

No recall of social worker

Point of contact

Opinion of help overall

Relationship with s/w

Help given to carers

Awareness of assessment

Info on care homes/services

Financial info

Type of discussion – practical arrangements, accommodation etc

Emotional support

Change of social worker

Face to face/telephone contact

6. Outcomes

Anything that could have been done differently re above

Overall opinion of post discharge situation

User Resignation to situation

Guilt for carers

Outcome for carers e.g. mixed, continued stress for carer

Views of care home e.g. isolation

Problems of adjustment e.g. embarrassment

Opinion of operation of care package at home

Multiple moves e.g. hospital to rehab to transitional care

Follow up

Review continued financial worry
Provision of equipment
Physiotherapy provision
Relationships with and between agencies
Carer/user relationship

Categories assigned to **staff focus group** data:

a. Changes to practice

Faster patient treatment and turnover
Delayed discharges legislation effects
Target culture
Computer related and administrative tasks
Effects of above on client-centred approach
Effects of above on older people
Positive effects of increased service development
Ageism

b. Interprofessional working

Communication between professionals
Interprofessional tensions
Valuing contributions of each profession
Older patients confusion re staff roles
Older people distinguishing between health and social care
Effect of reimbursement on relationships

3, Decision making

Information provision to older patients
Intimidating multidisciplinary meetings
Usefulness of home visits
Lack of choice of care homes
Involvement of users and carers in decisions
Effects of risk to patient on decisions
Discussing sensitive topics with patients

c. Outcomes for patients

Home care service provision problems

Multiple moves for patients

Moves to transitional care and rehabilitation

Attitudes to patients waiting for services in hospital

Appendix 11 - Comments from a voluntary organisation

Age Concern has gradually expanded direct services in the town to support older people and carers, which include a respite scheme and a hospital discharge follow up service. With regard to reduced length of stay and speedier discharges the latter team made the following observations based on their experiences:

- Older patients can often be discharged before a member of the team has been able to assess their needs and suitability for follow up services, on the ward
- Older people are going home 'less well' now requiring longer involvement with Age Concern, creating internal difficulties for them
- Increase in re-admissions noted
- Older people with memory loss can leave hospital without their needs being fully assessed
- Knowledge of medication and its use highlighted as a reoccurring problem for some older people post discharge
- Older people in hospital short term seem to have no access to a social worker or proper discharge planning but it can still be a hurdle for the individual to come out and no-one now to give them reassurance
- Concern about older people being placed in care homes far from families, spouses etc. post discharge

Most of the above, apart from point about medication were themes that occurred in the study findings particularly from staff comments. Age Concern also highlighted general pressure on social care provision regarding:

- Opening of new private hospital, which was commissioned, by PCT but reported lack of social work, OT or physiotherapy support to patients there. This may be a temporary 'teething problem', which may be rectified in due course.
- Less rehabilitation provided now as a social services' unit praised by SSI inspectors has closed
- Problem with older people being able to have a bath at care home, lack of day care and no space apparently.
- Difficult to obtain home care support post discharge if have a spouse

- Apparent reluctance for home care to assist with shopping – trying to encourage use of Internet to order food etc.
- Concern about isolation of older people in local care homes. Age Concern has a befriending service which is used in this context and has been very popular

Apart from the last one which was a theme from study findings, the above points did not arise in the study data, possibly because mostly older people with more complex needs all of whom had been seen by a care manager were referred to the project.

Appendix 12 - Conference papers and publications connected to thesis

Publication

Emergency Care Specialist Library Management briefings: Delayed hospital discharge: the social care perspective (2007 update). Available at:
<http://www.library.nhs.uk/emergency/ViewResource.aspx?resID=262787&tabID=290&catID=1414>

Conferences Papers

March 07: Glasgow University, JUC/SWEC Research Seminar
Poster presentation: 'Views of Hospital Discharge Informing Social Work Practice' (see Appendix 13)

Sept 06: Bangor University, British Gerontology Society Annual Scientific Meeting
Joint Paper: 'Older People, Communication, Information & Decision making'

Feb 06: Kings College, London. British Gerontology Society, research students' conference.
Paper: 'Reflexivity and Flexibility in Research'

Sept 05: Bournemouth University, JUC/SWEC Research conference
Poster presentation: 'The Role of Social Work in Hospital Discharge'

April 05: York university, SPRU 'Cash and Care' Conference
Poster presentation: 'older peoples experience of hospital discharge'

March 05: ESRC National Care Homes Forum seminar, Gosforth.
Paper: 'Moving from Hospital to Care Home'

Sept 04: Queens University, Belfast, JUC/SWEC Research Conference
Poster presentation: 'Older People, Social Work and Hospital Discharge'

Appendix 13 – Poster



Views of Hospital Discharge Informing Social Work Practice
Sue Fowler, University of Northumbria, Newcastle upon Tyne, UK
susan.fowler@unn.ac.uk



Background/Reasons for study

Listening to the voices of older people as largest user group of health/social care

- Closer working with health
- Managerialism and rationalisation
- Community Care (Delayed Discharges) Act 2003

Research Aims

In the study context of acute hospital, to explore:

1. How older people leaving hospital & their carers experience the discharge process, focusing particularly on social work activity
2. How social work operates and relates to other professions in this multidisciplinary setting post reimbursement?

Methods

This is a small scale **qualitative PhD study**:

- 49 users and 15 carers were recruited via hospital social workers
- Most users interviewed **post** discharge about their experiences, using semi-structured agenda
- 3 focus groups of health and social work staff involved
- Frequent visits to social work office over 2 year period
- Sessions taped, transcribed and analysed thematically

Findings summary: 1. User/Carers

Overarching thematic groups used to organise data:

- Loss e.g. of independence, home
- **"It was a shock, I expected to go home and just immerse" user** on plans for leaving hospital
- Being involved in decision making
- **"They all seemed to know but I haven't actually talked to them" user** on behind the scenes plans for her discharge
- Adjustment
- **"Impressed by it and the follow up as well" carer** describing social work input before/after discharge
- Relationships
- **"I didn't see enough of them to form an opinion" user** on lack of time spent with social worker

2. Staff Groups

Thematic groups:

- Changes to professional roles: **"his just like ordering a takeaway pizza" social worker** on care managing in hospital
- Inter professional working
- **"Them and us completely separate camps now even it we?" A doctor** on relationships with social workers
- Outcomes
- **"He still this very medical model, not interested in the social situation" Occupational therapist** on prevailing attitudes to older patients

3. Themes common to all groups

- Increased speed of assessment, treatment and discharges
- **"you wouldn't expect a young or person with a fractured knee to go home within 2 days- why are they expected a day or two to" DT** on orthopaedic discharge
- Issue of information and support for users and carers
- Lack of choice of care post discharge
- Increase in NHS facilities but shortage of health and social care staff

Discussion

Constructing alternative models of SW :

- Challenges – hidden, powerless, administrative, retreating, rushed care management
- Positive view – social work discourses, ability to negotiate, the social work relationship persisting against all odds
- Social work as a **balancing act**

Conclusions

"I try to visualize it as a slit of glass, I can see it but I'm not part of it. I think the job comes from to you and them – you and that person", hospital social worker's view of the role

- Evidence of older user/carer need for social work in hospital, but is it disappearing?
- Tensions in interprofessional working in hospital
- Reflections on study e.g. methodology & difficulties in discerning/describing practice
- Areas for further exploration e.g. psycho-social effects of fast turnover for elders in hospital

Glossary of terms used

BASW – British Association of Social Workers

CAT – Change Agent Team set up by the DH to promote joint working and good practice around hospital discharge

CHAI – Commission for Healthcare, Audit and Inspection

CO – Carer/close relative to service user, interviewed as participants for the study

COREC – Central Office of Research Ethics Committees, since 1.4.07 NRES – National Research Ethics Service

CSCI – Commission for Social Care Inspection

CQC – Care Quality Commission

DH – Department of Health

D/L – Discharge liaison sister who participated in the study

DR – Consultant in elderly medicine who participated in the study

EMI – Elderly Mentally Infirm, category of care home registration

FACS – Fair Access to Care guidance

GSCC – General Social Care Council

IFSW – International Federation of Social Workers

JRF – Joseph Rowntree Foundation

LA – Local Authority

LREC – Local research ethics committee

MDT – Multidisciplinary team of professionals working in the hospital with older people

NAO – National Audit Office

NHS – National Health Service

NISW – National Institute of Social Work (replaced by SCIE)

NSF – National Service Framework (NSFOP – NSF for older people)

OT – Occupational therapist participant who contributed to the study

Physio – Physiotherapist participant who contributed to the study

REC – Research Ethics Committee

Reimbursement – Arrangements for LA's to pay acute hospital trusts for post-assessment bed days under Delayed Discharge legislation (Great Britain, 2003. *op.cit.* and DH, 2003c)

SAP – Single Assessment Process

SCIE – Social Care Institute for Excellence

SSD – Social Services Department

SSI – Social Services Inspectorate

S/W – Social worker participant who contributed to the study

UO – Service user participant interviewed for the study

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